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The CCSS Bulletin

A publication for citizen participation in the Comprehensive Community Support System

Massachusetts Department of Mental Health July 1995

Welcome By Commissioner Eileen Elias:

I am pleased to announce that DMH is implementing its second three-year CCSS planning process.

The Department of Mental Health's Comprehensive Community Support System's (CCSS) planning efforts began in September of 1991. At that time, hundreds of consumers, family members, state and provider staff and interested citizens worked to develop principles and standards to guide the planning and restructuring of DMH areas - through the establishment of local CCSSs. More than 1,800 constituents became involved in the development of the detailed first three-year plans for each of the 33 CCSS geographic service areas. The three-year plans (for fiscal years '94, '95, and '96) reconfigured existing resources to meet many service priorities across the state. Consumer and family participation injected a new dimension regarding services and programs including the following:

- ⇨ *Responding to linguistic and cultural minorities;*
- ⇨ *Addressing the needs of consumers who have a dual diagnosis;*
- ⇨ *Improving transportation services;*
- ⇨ *Improving access to supported education and employment opportunities;*
- ⇨ *Reconfiguring child/adolescent services to expand home-based, school-based and wrap-around services;*
- ⇨ *Involving citizens and consumers in quality improvement projects, to address the quality of life issues in residential programs;*

This CCSS Bulletin will keep you informed about the next three year CCSS planning process and what needs to occur. Currently we are revising and expanding the previously submitted fiscal year (FY) '94-'95-'96 CCSS plans for FY '97, '98, and '99. We must continue to strengthen the CCSS planning process to ensure that the services provided by the Department are determined locally. We also need to refine the fiscal component of the '95 CCSS plans in such a way that these plans become the basis from which the Department will build its future budgets. Over the course of FY '96, DMH will work with constituents to understand the budget development process so that DMH budget submissions are based on CCSS planning.

Most of you are already aware of the Department's negotiation with the Division of Medical Assistance/Medicaid. These negotiations began as a way to clarify the appropriate role and authority of DMH and DMA/Medicaid, and to eliminate the duplication of acute care services provided by two separate organizations. By designing a system of care whose resources are used efficiently, DMH will redirect efficiency and expanded revenues back into its CCSSs to meet the needs and preferences of consumers as identified by the locally defined CCSS plans. Each CCSS's priorities serves as the primary blueprint for the allocation of these resources as they become available.

The CCSS Bulletin is a statewide vehicle for education and cross-fertilization of ideas among constituents and DMH. This bi-monthly publication provides a forum for sharing ideas and innovations, and bringing up-to-date information on statewide initiatives and projects to you regarding anti-stigma efforts, legislative issues, housing matters, and new findings in the treatment of people with mental illness. I encourage you to take advantage of this opportunity and use the CCSS Bulletin as a forum for your ideas.

Eileen Elias

What is a Comprehensive Community Support System anyway?...

[v.1 no.1]

History and Purpose of CCSS

In 1991, the Massachusetts Department of Mental Health made a commitment to implement statewide a model of integrated consumer centered services known as the Comprehensive Community Support System (CCSS). The model grew out of a series of meetings at the National Institute of Mental Health in the mid 1970s. The CCSS addressed the need to provide people with serious mental illness an array, not only of services, but also of supports. The CCSS coordinates the clinical and rehabilitative components necessary to sustain a safe and satisfying life in the community so that people with serious and long-term mental illness can live in the least restrictive and most productive environment that is consistent with their individual needs and potential.

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INSIDE:

Past CCSS Planning Process, what has come out?

Highlights and the Effectiveness of Citizen Advisory Board Participation statewide:

In the Western Mass. Area...

...Consumers, family members and people from the community are coming to the same table to discuss the issues, but they are still struggling to work together and learn from each other. There is empowerment of families through AMI and empowerment of consumers through consumer organizations, but the empowerment gained from being heard and understanding each other's points of view and concerns is not yet happening.

Through CCSS planning process the Western Mass. Area was able to:

- ✓ *Make improvements in service accessibility and responsiveness, especially responsiveness to linguistic and cultural minorities, or mobility or hearing impaired consumers in some CCSSs.*
- ✓ *Obtain a federal grant to hire professional mental health workers for the Russian and Cambodian immigrant and refugee communities.*
- ✓ *Improve transportation services for consumers by making sure all clubhouses/social clubs had vans or access to transportation.*
- ✓ *Improve consumer access to both education and employment generic community services.*

...In the Central Mass. Area ...

...More consumers became interested in participating in the process because of networking with other consumers that are already serving on planning committees.

The participation of consumers and family members in the CCSS planning process provided much more direct feedback to the Area regarding services, which had more of an impact on producing changes and results.

One CCSS Chairman has drawn in a host of community leaders from the city, housing authority, Visiting Nurses Association and community college.

Through CCSS planning process the Central Mass. Area was able to:

- ✓ *Form three task forces across the Area to address the*
- ✓ *needs of consumers who have a dual diagnosis of mental illness and substance abuse. This brought a lot of cross-provider participation as well as consumers and family members.*
- ✓ *Develop a program providing early intervention to young children who are exhibiting signs of emotional disturbance. This program is generating interest among child-serving agencies because of its flexibility.*

...In the MetroWest Area...

...CCSS Advisory Board meetings at each site were well attended by all constituents. The Advisory Boards provided a mutual learning experience in which family members came to see the consumers' strengths, and consumers were able to see family members as

CCSS-BULLETIN MISSION and VISION

As the Department of Mental Health moves into the next chapter in the development of a Public Managed Care system, we must affirm our committment to the importance of constituent participation and to the Comprehensive Community Support System (CCSS) model. We must also acknowledge that committment and good training are critical to the effectiveness of participation and to realization of the vision of Comprehensive Community Support System. Each month this bulletin will provide you the "news you can use" to inform and educate you about citizen participation and development.

We are interested in your ideas:

Write to us:
"The CCSS Bulletin"
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Send us a Fax at:
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tpizzuti@state.ma.us or
amadigan@state.ma.us

real people who are interested activists, not just parents. This resulted in good collaboration between all participants.

Through CCSS planning process the Metro West Area was able to:

- ✓ *Form a committee involved with the development of a land re-use plan for Metropolitan State Hospital.*
- ✓ *Held and participated in a legislative breakfasts.*
- ✓ *Direct the Area's programming for this year, including the Area's single residential code program design, through the use of the CCSS plan which served as a blue print. The CCSS Plan itself serves as an ongoing template for each CCSS meeting over the course of a year. CCSS Transportation Committee put together Taxi Service for consumers.*
- ✓ *Initial phase of the development of supported education plan.*

...In the MetroSouth Area...

...Citizens and consumers have worked on quality improvement projects, especially to address the quality of life issues in residential programs. Consumers participating in the Area, CCSS Advisory board and sub-committee structures have given valuable input into the service planning process.

Through CCSS planning process the Metro South Area was able to:

- ✓ *Creation of C.A.U.S.E. (Consumers and Alliance United for Supported Education), an active and ongoing committee whose mission is the expansion of program and hiring of specialized staff across the Area.*
- ✓ *Establish a consumer-run transportation company in both Metro South CCSSs.*
- ✓ *Hired consumers into DMH Area office as well as provider clerical and consumer relations positions.*

...In the Southeast Mass. Area...

...Through training, the concept of Public Managed Care became a reality to Advisory Board members and the community. The concept is now well known beyond DMH.

Feedback loops within the governance structure provide stakeholders with information. Membership of Area Board includes members from CCSS Advisory Boards and Boards of Trustees.

Through CCSS planning process the Southeastern Mass. Area was able to:

- ✓ *Direct comprehensive housing reorganization that rationalized housing throughout Area in conjunction with single residential code.*
- ✓ *Identify need for specialized services for people with mental illness and organic brain disorders.*
- ✓ *Joint Commission on the Accreditation of Healthcare Organizations (JCAHO) was extremely interested in CCSS planning process and was very pleased with the level of stakeholder participation across Southeastern network.*

...In the NorthEast Area...

...Participants in process become strong advocates for mental health issues with legislators and support other public relations activities.

CCSS Advisory Boards encouraged active participation of multi-cultural groups to make services more accessible for adults and children/ adolescents.

Constituents are better prepared to participate in evaluation committees at Area level because of training and participation in CCSS process.

Process encouraged the establishment of quality improvement activities and participation in Area Quality Council by consumers and family members to affect positive outcomes without emotional involvement. Participatory process empowered consumers and established allies among constituents.

Through CCSS planning process the Northeast area was able to:

- ✓ *Increase accessibility to non-mental health social services in community, i.e., substance abuse, transportation, elder services, etc..*
- ✓ *Encourage more cross-training between providers within CCSSs for both mental health and non-mental health providers.*
- ✓ *Establish linkages with community colleges, Mass Rehab. Commission, and Department of Employment and Training for supported employment and education opportunities.*
- ✓ *Provide Lawrence with a Hispanic case management team, services for people with a dual diagnosis, and housing programs for Hispanic consumers.*
- ✓ *Provide Lynn a city-wide multi-cultural task force to raise awareness, pool resources, and provide sensitivity training.*
- ✓ *Provide Lowell with a Cambodian case manager and pushed to recruit multi-lingual staff for a residential program.*
- ✓ *Lowell CCSS received a grant to target Southeast Asian population for residential and day programming. Set priorities for areawide restructuring goals.*

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Learning Opportunities...

CONFERENCES and FORUMS,

Held in Worcester, Boston, Framingham, and Plymouth

If attendance at several recent conferences is a measure of interest in mental health issues, then it is clear that the citizens of Massachusetts care about what is happening in this field. Consumers of services, their families, professionals, and the general public have filled auditoriums to learn about the treatment, recovery, and rehabilitation of people with mental illness, and how it is possible to participate in the planning for the way services are made available to them.

Citizen Participation Learning Conference

Worcester, April 29, 1995

On Saturday, April twenty-ninth, over a hundred people gathered at Worcester State Hospital to brainstorm ideas about improving the experience of voluntary participation for DMH constituents and the value of citizen participation for DMH.

It was an opportunity for an honest dialouge about sometimes conflicting expectations and a lack of clarity about the role of diverse constituents.

The revision of regulations and changes in formal, appointed advisory board structure to allign with the DMH Areas and CCSSs has resulted in a three part structure of 15 member appointed boards: the State Advisory Council at the State Level, the seven Area Boards, and thirty-three CCSS Boards for a total of 615 appointed members. Participants expressed confusion about the role of each level of citizen advisory structure and the relationship between the different boards.

The learning conference was also an opportunity for DMH to clarify its committment to the value of additional constituent participation, particularly but not exclusively in ongoing CCSS planning.

Appointed citizen advisory board members participate with additional consumers, family members, and interested citizens who may choose not to seek appointment to an advisory board.

Many people referenced the positive experience of many diverse stakeholders coming together and pooling their mix of skills and experiences.

After introductory remarks by the Commissioner and reports on current board activities by Gloria Boudreau of Western Mass and Michael McNiece of Metro South, the participants got down to work. Breaking into five groups, they tackled such issues as board training, board recruitment, and communication with the community as well as with other Department entities.

The recommendations were wide ranging, creative, and specific and were submitted by each group at the end of the day. All of this material is being organized into a set of proposals for improved citizen participation which will be shared with attendees and used to improve the effectiveness of citizen participation

Over eighty percent (80%) of the evaluation results indicate high satisfaction of the participants with the event. The energy which flowed that day will fuel the momentum to overcome impediments and tackle the challenges ahead.

Stay tuned - we will continue to update you on progress.

Trauma and Mental Illness: What Helps & What Doesn't?

Framingham, May 12, 1995

Reported by Nicki Glasser

It is estimated that at least 60% of all people who have been diagnosed with mental illness have also been victims of violence and abuse...

The Department of Mental Health took another step toward higher quality care and recovery by recognizing trauma as a major player in triggering and exacerbating long term mental illness. The reality of trauma histories among child and adult DMH con-

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sumers and the absence of appropriate services and support was a dominant concern of many CCSS planning recommendations. The DMH Training Program, headed by trauma expert Dr. Ray Flannery, sponsored a one day conference entitled, "Trauma and Mental Illness: What Helps? What Doesn't? on May 12 at Framingham State College. One hundred-fifty people attended the free conference, half of whom were consumers of mental health services. Participants had the opportunity to learn from the experience of consumers, in addition to having dialogue with professionals in the field. What set this conference apart from other trauma conferences was its highlight on DMH consumers, giving them a forum to discuss their experiences and explore ways the system can better serve their needs.

Valerie Fletcher, Deputy Commissioner for Program Operations and Chairman of the DMH Trauma Task Force of DMH opened the day by welcoming the participants who included clinical professionals, consumers and administrators. During the morning, an overview of the problem was delivered by Dr. Elaine Carmen, a psychiatrist internationally known for her work in trauma treatment. Dale Walsh, a professional and a survivor, also gave a powerful talk on her struggle to recover from traumatic childhood experiences and major mental illness.

Late morning workshops offered a chance to discuss informally what the mental health system does that is helpful and to make recommendations for change. There was lively, heartfelt give and take where both consumers and professionals spoke honestly about their experiences. Much discussion centered around the unfair balance of power which staff holds and how to bridge that gap.

In the afternoon, the conference participants broke into six workshops, each approaching a different topics by asking such questions as, "Depression/ Emotional Numbing: What Does it Mean?" and "Manipulation: Is it Desperation or Staff Frustration?" For the topic of substance abuse the workshop asked, "Is it a Problem or a Solution?" and featured, like the others workshops, consumers with relevant experiences exchanging views and establishing a dialogue with other participants. Members emphasized the importance of dual diagnosis treatment facilities and the need not to turn one's back on consumers with a substance abuse problem.

The newly formed Task Force on Trauma will be reviewing the results of the conference and will use the ideas and recommendations of Conference participants to shape its goals and objectives including additional trainings. Their mission is to assist the mental health system to be more responsive to the needs of adults, children and adolescents who have experienced trauma. The Task Force will develop recommendations for policies and practices that will include awareness, sensitivity, and skill training to best serve this population.

Schizophrenia and Reintegration

Plymouth, May 23, 1995

Co-sponsored by Baybridge Clubhouse, AMI of Mass, DMH- Plymouth, Cape Cod and the Islands and by an educational grant from Sandoz Pharmaceuticals.

At the John Carver Inn, a CCSS welcome from the Plymouth community was delivered by Dorothy Chase, Ph.D., Plymouth Area Site Director. There, in the land of the first Pilgrims, Dr. Chase likened her audience to modern day pilgrims on a journey whose goal is a better life for people with mental illness, a journey which will not end until better treatments and even cures are found for these debilitating diseases.

Some of the topics addressed were "The Social Texture of Community Living," by Andreas Laddis, M.D., Cape Cod Medical Director, and "Recovery as a Process," by Sharon Sousa, MSW, D.D.Ed. from the Corrigan Mental Health Center. Opening and closing remarks were made by Jean Crocker, Chairman of the Baybridge Advisory Board and Winthrop Alden, President of the Massachusetts Alliance for the Mentally Ill.

But the star of the day was Lori Schiller, author of 'The Quiet Room,' a book which tells the tragic story of a young woman who spent nine years of her life in and out of mental hospitals, until a new and then experimental medicine called clozapine, rescued her. Lori Schiller wrote this book using the journals she kept during those terrifying lost years.

She and her mother, Nancy, recounted in heart

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What's each CCSS Supposed to Do ?

Each CCSS is a mix of state and contracted services located in a natural service area with a common geographic, political, and demographic profile. Every CCSS develops an integrated service system that eliminates fragmentation and duplication through coordination and maximization of the role of services provided by non-mental health resources (e.g., generic health, housing, education, employment services) and natural supports such as friends, family, peer, civic, and religious constituents. The CCSS is the basis for the DMH Public Managed Care System. The CCSS focuses on improving the local system of care in which the individual gets what they need and want, when they need it and no more than they need. It is designed to minimize dependence on acute services and enhance access and choices to an array of continuing care options.

How can CCSS be the basis for the DMH Health Care Network?

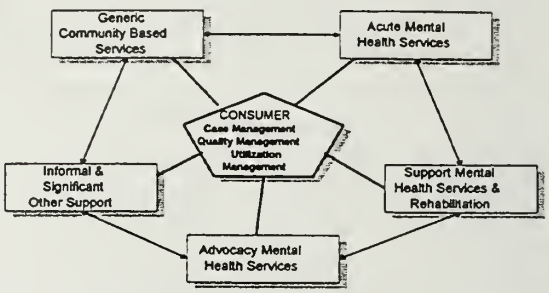
The primary mission of the Department of Mental Health is to provide services to citizens with long-term mental illness, early and ongoing treatment for mental illness, and research into the causes of mental illness. The Department also provides emergency, evaluation/assessment, and short-term treatment for any child, adolescent, or adult experiencing an acute mental health crisis who requests assistance.

For every DMH geographical area there will be a number of CCSSs performing a core set of essential functions by providing: Acute, Support Rehabilitation, Advocacy, Generic, and Informal Support Services to a defined population of individuals within defined geographical boundaries.

An Area Health Care Network is a central integrating structure in each and every geographical area, overseeing and coordinating all of their CCSSs. Each of these networks' central structure is represented by the DMH Area Offices. The task of an area office is to coordinate and integrate areawide services provided at the Comprehensive Community Support Systems (CCSS) levels.

The Area Network functions also include a range of activities like Total Quality Management (TQM), and Continuous Quality Improvements (CQI), in which a bottom-up approach will ensure that services not only meet predetermined criterias, but also a minimum required level of quality.

COMPREHENSIVE COMMUNITY SUPPORT SYSTEM



Service Delivery Components of CCSS

1) Acute Services

Acute services component includes: emergency services, acute inpatient hospitalization, partial hospitalization, and alternatives to hospitalization.

2) Support/Rehabilitation

Support/Rehabilitation component includes: Skills training, residential support, clubhouses, social clubs, group and individual therapy, transitional and supported employment.

3) Advocacy Services

Advocacy Services include: Case management, legal assistance, family support, and consumer empowerment activities.

4) Generic Services and Supports

Generic Services include: Linkage and support for accessing needed non-mental health services (e.g., health care, Department of Employment and Training, Mass. Rehab. Commission, Department of Education) and local public and private services (e.g., YWCA, Area Agencies on Aging, Visiting Nurses Associations).

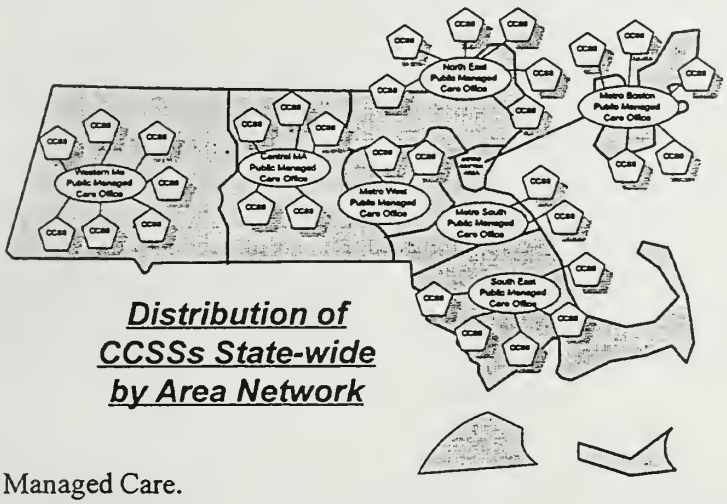
5) Informal/Significant Other Support

Living in the community is not synonymous with community integration. The CCSS must recognize, encourage and support linkage to the ordinary but critically necessary support of other consumers, family members, religious/spiritual communities, landlords, neighbors and friends in order for consumers to achieve meaningful integration.

How does a CCSS get Planned for?

The Department of Mental Health is committed to ensuring that the CCSSs which are developed reflect local needs and are constantly refined through annual submissions of revised CCSS plans. The planning process must include the active participation of the

diverse constituents at the local level. Ad Hoc Area Planning Committees are established with consumers, family members, interested citizens, provider staff, and state staff to assist in the process. This broad base of participation will ensure that the system is responsive to the local mental health needs, and is consistent with the principles of DMH Public Managed Care.



Distribution of CCSSs State-wide by Area Network

CCSS plans are developed by Natural Service Area staff, based on advice and suggestions from the Ad Hoc Planning Committees\Sub-Committees, and will outline the tasks and time frames for the development and continuous improvement of comprehensive community support systems in that area.

Who are the participants in the CCSS Planning Process?

CCSS Citizen Advisory Board Local level of the formal DMH citizen advisory structure. Ongoing CCSS planning occurs through an ad hoc planning committee(s) which includes members of the CCSS Citizen Advisory Boards as well as other constituents. Plans are submitted to the CCSS Citizen Advisory Board for approval before being submitted to the Area Board and Area Director.

Participants in the CCSS Planning Process:

CCSS Site Manager

Coordinates the ongoing planning process for the CCSS and ensures the provision of requisite information and staff support to citizen participants.

Area Advisory Board

Area level of the formal DMH Citizen Advisory structure. Receives, analyzes and approves the CCSS plans for the Area in tandem with the Area Director.

Area Director

Responsible for oversight of needs assessment and planning for the entire area inclusive of all CCSSs and approval of the annual plan submission to the Commissioner and SAC along with the Area Board.

State Advisory Council

State level of the formal DMH Citizen Advisory structure. Participates in the analysis of the annual CCSS plan submissions and approves the plans and agency priorities in tandem with the Commissioner.

Commissioner

Final authority for approval of annual statewide CCSS plan and the agency priorities.

(Continued from Page 3)

...In the MetroBoston Area...

...Participation continues to promote constituent ownership of programs and services and an investment inimproving quality, which then holds the Area Office accountable for continuous quality improvement activities.

Consumer and family participation injected a level of reality regarding services and programs that DMH staff did not/could not have.

Through CCSS planning process the Metro Boston Area was able to:

- √ ***Reconfigure their child/adolescent system, resulting in the need for fewer long-term beds and more home and school-based wrap-around services.***
- √ ***Identify neighborhood service needs for the Casey initiative.***

Restarting the CCSS planning process at Massachusetts Mental Health Center to respond to consumer and constituent concerns.

Solomon Carter Fuller MHC: consumers participating in process were adamant about the siting of residential and service programs in safe neighborhoods.

wrenching detail what those years and her subsequent recovery have been like for Lori and her family. They spoke to an audience of professionals, family members, and consumers, a term Nancy Schiller deplores. "The insurance people love it. When did you ever hear of a cancer patient called a client or consumer? When is schizophrenia going to be considered a major illness?"

Win Alden summed up the day, suggesting that the participants take with them, not only the memory of a lovely Spring day and the excellent packets of information but a sure sense of HOPE. The resounding applause said it all.

Recovery from Psychiatric Disability: Implications for the Training of Mental Health Professionals

Boston, May 10, 1995

Recovery from Psychiatric Disability (**what a welcome concept!**) was the subject of a conference held at the State House under the sponsorship of the Department of Mental Health and the Alliance for the Mentally Ill of Massachusetts in collaboration with the Center for Psychiatric Rehabilitation, Boston University, and Vinfen Corporation.

In a talk which earned her a standing ovation, Patricia Deegan, Ph.D. spoke from her own experience of recovery which she defines as a process not a cure. Dr. Deegan, founder of the National Empowerment Center in Lawrence, Massachusetts, told her listeners that everyone, including those who have seen their lives and dreams shattered in the wake of mental illness, must face the essential challenge, "who can I become and why should I say yes to life?"

She challenged the instructors and trainers of the next generation of mental health professionals to suspend their perceptions of people as chronic mental patients and to see the individual as a hero, who has survived great losses, who is not just a lot of negative symptoms, lazy, unmotivated, "low functioning", but a person whose "not caring' is an adaptive strategy used by desperate people who are at risk of losing hope.

Following this, Courtenay Harding, Ph.D. of the University of Colorado School of Medicine, presented evidence which challenges the most commonly held myths in psychiatry about schizophrenia, myths which routiely predict pessimistic outcomes and which effect and limit the scope of treatments.

Both Deegan's and Harding's presentations provided exciting implications for new treatment and training for professionals, as well as a hopeful message to consumers and their families. If you would like a copy of Dr. Deegan's or Dr. Harding's remarks, please call Tony Pizzuti at 617-727-5500, extension 329 or Ann Madigan at extension 242.

20TH ANNUAL IAPSRS CONFERENCE

Boston June, 1995

The International Association of Psychosocial Rehabilitation Services held its annual convention at the Sheraton Boston June 5-9. IAPSRS speaks for people in the psychosocial rehabilitation field whose mission is to advance the role, scope, and quality of services which facilitate the community readjustment of people with psychiatric disabilities. The conference brought together agencies, practitioners, families, and consumers of these services.

It featured well known speakers such as Bernard Arons, M.D., Director of the Center for Mental Health Services in Rockville, Maryland, and William Anthony, Ph.D., Director of the Center for Psychiatric Rehabilitation at Boston University, and Joel Slack, Director of the Office of Consumer Affairs in Alabama. Its institutes and workshops covered a spectrum of rehab issues, e.g., Job Placement, Housing and Community Supports, Managed Care, Multi-cultural Perspectives.

The Department was pleased to sponsor six thousand dollars worth of scholarships for family members and consumers to attend.

DMH ANTI-STIGMA CAMPAIGN

"At a time of growing sensitivity to racist and sexist language, no such caution governs the use of the vocabulary of mental illness..." *TIME, February 15, 1995.*

When the U.S. Secretary of the Interior referred to a person with a physical disability as a "cripple", the ensuing outrage forced his resignation.

When a City Councilor in a small Massachusetts town warned, "there's a nigger in the woodpile," newspapers were filled with angry letters, in spite of his apologies.

When a Boston newspaperman wrote about people with mental illness as "nut cases," claimed that they "act like toothbrushes" and called the hospitals where they receive care "funny farms," there was no public outrage, no apology.

Not only barbarous and inhumane, stigma poisons everything surrounding mental illness:

- *Funding is difficult to obtain for services and research*
- *People don't seek help when it's needed and when it can be most helpful*
- *Housing, job and educational opportunities are restricted*
- *Mental health field is less attractive to professionals.*

The Department of Mental Health believes it's time for society's attitudes to change. In order to do that, the Department has launched an anti-stigma campaign. Area Directors and CCSS Site Directors have already responded to a Central Office questionaire which included the question:

"If the Department could undertake ONE major project to address stigma, what would you recommend?"

How would you answer that question? If you have ideas, thoughts to share, experience or knowlege of what works or of what doesn't, call **Ann Madigan at 617-727-5500 x242.** Each issue of the Bulletin will bring news to you from the Stigma front. *(It is a battle, and it will be won!)*

Stigma *n.,*

1. Archaic. A mark burned into the skin of a criminal or slave; a brand.

2. A mark of infamy, disgrace or reproach.

1-800-221-0053 Information and Referral

(toll-free in Massachusetts)

A part of the Massachusetts Department of Mental Health, run by consumers to provide basic information and/or refer you to the appropriate department, agency, or people, regarding:

Community resources - Complaints - Consumer-run groups - Discrimination issues - Family support - Social security.

We also offer statewide library resources, including videos, books, and articles pertaining to mental health issues.

You may call anytime during regular business hours. If there is no answer, please leave a message and either Pam or Judy will return your call as soon as possible.

Creative Approaches to Mental Health Services:

CRISIS PLANNING

We all know what to do when life is humming along with only its usual twists and turns. It's when we're hit by the unexpected, the extra demand for our time and resources, the quick and sudden storm that swamps us that we promise ourselves to be better prepared next time.

This may mean something as simple as leaving an umbrella in the office or checking the gas gauge in the car. It may mean increasing the savings account or updating employment skills. It always means thinking about a problem in a quiet, reasonable way before it engulfes us.

This is what the Crisis Plan Development Project seeks to do with consumers, families, friends, and providers. It is a collaborative effort of the Massachusetts Department of Mental Health, M*Power, the Alliance for the Mentally Ill (AMI) and the Greater Lawrence Mental Health Center (GLMHC) through a federal Community Service Program (CSP) for mental health services grant.

Crisis planning will give consumers the opportunity to prearrange the responses and interventions they would like to have available to them during a psychiatric crisis. The plan will be developed by the person who is receiving services from the Department of Mental Health, with assistance provided by their Case Manager. The focus of all family, friend and provider input will be to define what they will do to help the consumer in a crisis. No information on any aspect of the plan can be shared without the permission of the consumer.

This project is in a design stage: training curriculum, pilot crisis plans, and method for evaluating the project are underway.

For more information, please call one of the Project Contact Staff:

Mary Margaret Moore, DMH 617-727-5500 x419

Deni Widfelt, M*Power 617-464-1400

Barbara Morganthau, AMI 617-426-2299

Tony Berardi, GLMHC 508-683-3128

Interested in becoming involved in the CCSS planning?

BREAKDOWN OF NATURAL SERVICE AREAS/CCSSs & WHO TO CALL

WESTERN MASS.

James Duffy,
Area Director
413-584-1644

1 *Central/South Berkshire*
2 *Franklin/North Quabbin*
3 *Hampshire*
4 *Holyoke/Chicopee*
5 *North Berkshire*
6 *Springfield*
7 *Westfield*

NORTH EAST

Lorene Bourque,
Interim Area Director
508-851-7321

1 *Beverly*
2 *Greater Lawrence*
3 *Greater Lowell*
4 *Haverhill/Newburyport*
5 *Lynn*
6 *Wakefield*

METRO WEST

Theadore E. Kirousis,
Area Director
508-792-7400 2073

1 *East*
2 *West*

CENTRAL MASS.

Constance Doto,
Area Director
508-752-4681

1 *Blackstone Valley*
2 *Fitchburg/Leominster*
3 *Gardner*
4 *South Central*
5 *Worcester*

METRO SOUTH

Barbara A. Leadholm,
Area Director 508-359-7312 ext.600

1 *Newton/South Norfolk*
2 *South Shore/Coastal*

SOUTHEAST

John P. Sullivan,
Area Director
508-580-0800 ext. 201

1 *Brockton*
2 *Cape Cod*
3 *Fall River*
4 *New Bedford*
5 *Plymouth*
6 *Taunton/Attleboro*

METRO-BOSTON

Clifford Robinson,
Area Director
617-727-4923 ext. 301

1 *Bay Cove*
2 *Cambridge/Somerville*
3 *Lindemann*
4 *Mass. Mental Health Center*
5 *Solomon Carter Fuller*

Briefly Noted...

Consumer-Run Initiatives: a rise in popularity

Consumer-run initiatives in Massachusetts are now established in their third year. This year, a total of sixty-eight projects applied for funding, an impressive increase of almost 100% from last year. Next, a reviewing committee composed of consumers, staff and vendor representatives will be meeting to decide which projects will be funded. We will keep you posted.

Integrated Systems Promise Better Patient Care

Individual View on Managed Care:

As reported in Psychiatric News, April, 1995, of the American Psychiatric Association (APA) Neil J. Baker M.D., Chief for Mental Health Services for Group health Co-op in Seattle, an HMO system with 500,000 enrollees, report that Integrated Systems promise better patient care. According to Dr. Baker, managed care offers an opportunity to focus on preventive aspects of medicine while providing an integrated network of mental health, primary care, and other specialty services.

Dr. Baker described managed care as an ethical imperative to maximize patient care with finite resources: *"I think the mistake that psychiatrists and physicians make today is identifying managed care with the latest abuse in utilization review instead of thinking how we can participate in developing ethical principles and activating them in a responsible way"*

In the article, Dr. Baker refers to using resources outside the mental health care system in the community such as churches, places of employment, and schools to find ways to support people with mental illness.

His position regarding managed care is to endorse an integrative approach to care, working with patients and families to help them understand mental illness and how best to manage it.

"Making a Difference" with Community Services:

A new federal report on homeless persons with serious mental illness, "Making a Difference," is based on the findings of five demonstration projects - one each in Boston, Baltimore, and San Diego, and two in New York. Nearly 900 persons participated. Most of them accepted and were effectively helped by community-based mental health programs, including intensive case management and comprehensive support systems. (Psychiatric Times / March, 1995). Bernard Arons, M.D., Director of the Center for Mental Health Services of the U.S. Department of Health and Human Services, says, "The results of this program demonstrate the extrordinary potential for changing the lives of people who are both homeless and suffer from a mental illness...these individuals cannot achieve their goals without systemwide support and understanding."

National Accreditation Sought by DMH Southeastern Area Network

The Joint Commission on Accreditation of Healthcare Organization (JCAHO) has been conducting a survey of DMH Southeast Area. The JCAHO survey team will speak with employees from area throughout DMH as part of the extensive evaluation of the DMH Area as a Network of Care.

The JCAHO is a privately funded organization focused on improving the quality ofcare provided to the public. By evaluating organizations and comparing them against an established broad set of performance standards, the JCAHO helps ensure that practices of mental health care services provided are uniformly performed and reviewed.

JCAHO accreditation, the most widely sought in health care industry, is the most comprehensive external review process available. Its findings are used by virtually every health care regulatory and contracting agency in the country, including the federal government for Medicare certification and the Massachusetts state government for hospital licensure. Although the JCAHO evaluation is sought on a voluntary basis, having its stamp of approval is an important standard in today's competitive health care market-place. Future issues of the Bulletin will carry additional information on the upcoming JCAHO visit. Those with specific questions are encouraged to call us.

Welcome to the First Issue !

of The CCSS Bulletin

The CCSS Bulletin

A publication for citizen participation in the Comprehensive Community Support System

v. 1 no. 2

Massachusetts Department of Mental Health August 1995

Next Round of CCSS Activities...

In conjunction with the late spring citizen learning conference held in Worcester, on Tuesday, June 27 there was a meeting between the DMH central office staff and field staff. As in the case of the conference the purpose of the meeting was to hear concerns regarding the improvement of the CCSS process.

At the meeting it was recognized that the volume of work to be done is enormous and that there is never enough time to accomplish things all we want to do.

The sequence of CCSS activities will be as follows:

The arduous task to develop Financial and Utilization Profiles at the CCSS and Area-shared levels is completed and being reviewed in Central Office. The DMH submission for FY'97 House budget development will be based on that information. Planned restructuring is expected to be incorporated in these submissions.

(Continues to Next Page)

Inside This Issue:

Funded: Experimental Comparison of the PACT and Clubhouse Models

The project is designed to determine the effectiveness of two different models of community rehabilitation with strong vocational components: the Program of Assertive Community Treatment (PACT) model, based on the original Training in Community Living model, and the Clubhouse model, based on the Fountain House program. Both of these models have been replicated extensively throughout the US as well as internationally, and both have well-developed dissemination and training programs. The proposed research would be the first direct comparison of the PACT and the Clubhouse models and the first experimental comparison of the Clubhouse model to another community service.

(Continues to Page 5)

Employment Program to be Expanded to all DMH Areas

Employment Connections, a Boston-area pilot program to employ people with mental illness who are or have recently been homeless, will be expanded, to seven other regions of the state as a result of a $2,116,725 three-year federal grant.

Since this collaborative project between the Departments of Mental Health (DMH) and Employment and Training (DET) began, more than 90 consumers have been referred to and are enrolled in the program. Of that number, 24 consumers are working with an average wage rate of $6.20 per hour.

The role of the Department of Employment and Training is to offer help with resume writing, identifying employment search skills, job readiness screening and sharpening of interviewing techniques. In addition to these services, DET will offer education and outreach services to DMH consumers and will become involved in developing and disseminating information related to the American with Disabilities Act (ADA).

Employment Connection will be expanded to projects statewide to serve an estimated 225 to 300 consumers, and like the Boston Project, they will be community-based offered through local DMH and DET office.

With some variation, each DET office will have a full-time employment counselor and a mental health consumer acting as a peer support and employment advocate, as well as a DMH employment support worker determining the auspice and locations.

DMH consumers will be referred to the DET offices through a single point of contact by DMH network of caseworkers, clubhouses and supported employment providers. Employment specialists will market the participant's talent and work with employers to develop a job placement that fits with a person's skill levels.

Never doubt that a small group of committed citizens can change the world. Indeed, it is the only thing that ever has.
Margaret Meade

Constituents at the CCSS level are in the process of identifying their ranked priorities for their CCSS allocations. They will submit their recommendations to the Area Board and Area Director to complete their review by September 15.

The next round of complete three-year CCSS plans (FY'97, '98, '99) will be due later this year.

A comprehensive training strategy for citizen participants will be developed as a collaboration of Central Office, Area and CCSS staff. The training components will include but not be limited to budget development and revised CCSS standards which accord with JCAHO Network standards.

There are two primary goals:

1) Ensure the integrity of constituents' participation in the development of local Comprehensive Community Support Systems, DMH's model for the integrated delivery of public mental health services and supports.
2) Weave CCSS planning into the infrastructure of the Departments in order to have logical coherence between that process and the variety of regular and special initiative activities of the DMH.

The following chart is the form to be used by each CCSS board to indicate types of services needed and the dollar amounts allocated for Fiscal Years '97, '98, and '99.

CCSS-BULLETIN MISSION and VISION

As the Department of Mental Health moves into the next chapter in the development of a Public Managed Care system, we must affirm our commitment to the importance of constituent participation and to the Comprehensive Community Support System (CCSS) model. We must also acknowledge that committment and good training are critical to the effectiveness of participation and to realization of the vision of Comprehensive Community Support System. Each month this bulletin will provide you the "news you can use" to inform and educate you about citizen participation and development.

We are interested in your ideas:

Write to us:

"The CCSS Bulletin"
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25 Staniford Street, Boston, Ma. 02114

Send us a Fax at:

617-727-5500 ext. 375

Send us E-Mail at:

tpizzuti@state.ma.us or
amadigan@state.ma.us

Comprehensive Community Support System Summary Plan

AREA :

NATURAL SERVICE AREA :

CODING				SERVICE COMPONENT	1997				1998				1999			
AREA	ORG Code	CCSS Comp	Prog Code	II. SUPPORTIVE MENTAL HEALTH AND REHAB SERVICES	Resources $	FTE's	Service Capacity	# People Served	Resources $	FTE's	Service Capacity	# People Served	Resources $	FTE's	Service Capacity	# People Served
		2		A. DAY AND OTHER NON-RESIDENTIAL SERVICES												
		2		CLUBHOUSE												
		2														
		2		DAY TREATMENT												
		2														
		2		TRANSPORTATION NETWORK BETWEEN PROVIDERS												
		2														
		2		SKILLS TRAINING WORKSHOP												
		2														
		2		B. HOME-BASED SUPPORT SERVICES												
		2														
		2		C. OUT-PATIENT CARE												
		2														
		2		D. RESIDENTIAL SERVICES												
		2														
		2		E. INTERMEDIATE AND LONG-TERM INPATIENT CARE / CONTINUING CARE												
		2														
		2														
		2														

(CCSS Three-Years Plan Chart)

Citizen Participation Learning Conference...a follow up

From notes taken and reports submitted by the participants at the Worcester conference of April 29, a picture emerges of what is important and needs attention in order to ensure the success of the CCSS and Area boards. The questions, concerns and recommendations presented that day propose solutions to the problems of 1) recruitment and retention of constituents 2) current advisory board structure and 3) current advisory board operation. Some of the suggestions are more practical than others; some are basic and general, while others are specific. Priorities must be established for a work plan.

WHAT PARTICIPANTS SAID:	WHAT PARTICIPANTS RECOMMENDED:

1) Constituents Recruitment & Retention

WHAT PARTICIPANTS SAID:	WHAT PARTICIPANTS RECOMMENDED:
☞ Recruited to do what? Mission unclear, need more information on goals and regulations.	✓ Need to have clear definition and guideline regarding the CCSS mission, goals, and regulations for board members (use a consistent language that makes sense and that is accessible).
	✓ Give citizens the sense of accomplishment that make voluntary services worthwhile
☞ Recognized potential contribution of citizens with diverse backgrounds.	✓ List all possibilities for citizens to get involved.
	✓ Promote process locally and statewide.
	✓ Standard orientation and education for members of: CCSS Boards, Area Boards, State Advisory Council.
☞ Expressed concern about the lack of orientation to DMH system and training on how to run meetings.	✓ Provide training and education as incentives to involvement.
	✓ DMH must provide needed and timely information so that board members can do their jobs.
	✓ Set smaller goals and highlight achievements along the way.
☞ Expressed concern about maintaining interest and continued participation.	✓ Have periodic focus groups to assess problems and set priorities.
	✓ Conduct exit interview for members leaving boards.

2) Boards Structure

WHAT PARTICIPANTS SAID:	WHAT PARTICIPANTS RECOMMENDED:
☞ Expressed concern about boards' organization and design not being clearly defined in relation to the CCSS planning process.	✓ Review the role and functions of the formal appointed boards.
	✓ Balance and target expectations and goals.
	✓ Complete annual reports on bards' activities.
☞ Unorganized tasks and structure of formal citizen boards.	✓ Define linkages between CCSS-Area Boards, SAC, and Board of trustees.
	✓ Annual CCSS Conference to deal with break-out task forces.
☞ Wow do we know anyone hears or uses our recommendations?	✓ Have informational programs in local community colleges providing information about DMH and mental illness.
☞ How will various constituents and DMH staff communicate?	✓ Consumer presentation to school groups and community groups
	✓ Inform and educate constituents as how to use the Boards available to them.
☞ How will the community at large be included in the planning function.	✓ Build relationships with community at large.
	✓ Invite community members to participate.
☞ Everyone is responsible for recruitment leaving no one in charge of retention.	✓ Identify point person for recruitment purposes.

3) Boards' Operation

WHAT PARTICIPANTS SAID:	WHAT PARTICIPANTS RECOMMENDED:
☞ Too many priorities, too much paper, and too much reading required.	✓ Establish a management strategy for dissemination of information before a meeting.
☞ Define timelines for discussion and planning activities to be carried out	✓ DMH staff and board members will work together and ahead of time to identify the yearly activities to be carried out and their timelines.
☞ Infrequent and inconsistent meetings.	

(Continues on Next Page)

Continues from Previous Page

3) Boards' Operation

WHAT PARTICIPANTS SAID:	WHAT PARTICIPANTS RECOMMENDED:
☞ Agendas for meetings are not determined locally	✓ Need to have regular meetings which are stuctured.
☞ Feel for a tangibile 'product' of citizen participation.	✓ Identify and prioritize issues requiring attention.
☞ Problems with childcare, transportation, schedule, and other costs of participation.	✓ Put on table important issues; must be allowed to carry out roles and responsibilities.
☞ Need for clear, quick responses to inquiries of planning participants.	✓ Surveys of local consumers to identify issues of concers.
☞ Resistance to "new" approaches and views coming from outside DMH	✓ Provide training and education to achieve bottom-up rather than top down decision making process.
	✓ Use sub-committees/ad-hoc group from community focused on specific issues of interest to that community (i.e. supported ed., housing).
	✓ Make all participants aware of the subsequent effects of their recommendation to DMH
	✓ Defray cost of attendance for constituents.
	✓ Travel and other incentives to community and CCSS board meetings.
	✓ Adequate DMH support staff resources needed.

Dancin' Out: How Consumers Meet Their Social Needs...

a Newton/South Norfolk CCSS experience with Support Mental Health Services & Rehabilitation component of the CCSS.

by Aaron Needle

It must have been apparent to all constituents involved in the CCSS planning of Metro South Newton/South Norfolk that the emphasis on restructuring lay on clinical services, rather than social and recreational activities. These services often tend to be overlooked and don't rank high in the priority list. Examination of the strengths and gaps in the Metro South's CCSS planning activities created an awareness among some constituents and the recognition that recreational activities are as important as any other activities in consumers' lives and recovery process.

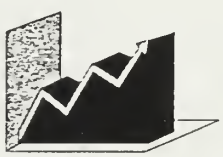
The idea for Dancin'Out spawned from these identified CCSS need which I combined with some of my personal life experiences. In fact, I had once worked as residential case manager for adults with severe mental retardation and became familiar with the South Norfolk Association for Retarded Citizens. ARC was founded on the premise that DMR wasn't providing some of the services that family advocates felt were wanted and needed. ARC's most popular event was the monthly social dancing, in which consumers had a wonderful time with minimum supervision or disruption.

I started liking dance in the years following my first hospitalization for mental illness. After taking some jazz dance classes I became involved with Dance Friday, a cooperatively recreational dance near my home. There I felt welcome, safe and unself conscious.

I felt I had all the experience required to organize Dancin' Out. Friday July 28th, was the first night in a series of monthly Dancin' Outs. The space was provided through the *Hyde Community Center* in Newton. We have met the cost for this event through contributions from people attending the dance. Additional resources were provided by consumers in the area who raised money from collecting bottles and cans in residences and programs. The plans for the next event are already underway and funding will be provided by a contribution by the Friends of Medfield.

Aaron Needle is an Advocate and a consumer and currently works at the Elliot House Clubhouse in Newton.

Is "Consumer Driven" Care on the Rise?



The Boston Business Journal dated July 14, 1995 reports the importance consumers' role in shaping and improving the delivery of health care. The journal feature reports that the non-profit Picker Institute helps medical professionals understand how patients feel about their care. The institute, affiliated with Boston Beth Israel Hospital, has joined an alliance with 67 other medical centers nationwide to provide patient satisfaction surveys. Surveys will be one tool used to determine whether consumers are getting enough care and whether they are satisfied. The Picker institute is headed by Dr. Thomas DelBanco, Chief of General Internal Medicine and Primary Care at Beth Israel Hospital, who will help develop surveys that hospitals can use to measure consumers' satisfaction and help the hospitals analyze the resulting data.

Learning Opportunities..

CONFERENCES and FORUMS... Washington D.C.; and Saint Paul, MN; Boston, MA.

The National Alliance for the Mentally Ill (NAMI)

held its annual convention July 19-23, 1995 in Washington, D.C. Its theme was "Research and Advocacy."

Each day of the conference was jam-packed with seminars, speeches and workshops with titles such as "Research, Can NIMH Meet the Challenge?," "What is This Thing Called Outcomes and Why is it Important in Managed Care?," "Supported Employment, Finding the Right Job." Some of the names on the program made hard choices for the participants: Nancy Andreason, MD,PhD, E. Fuller Torrey, MD, Stephen Goldfinger, MD, Agnes Hatfield, PhD. **Ask the Doctors Sessions** covered not only schizophrenia and affective disorders, but new research on obsessive-compulsive, panic, anxiety, and borderline personality disorders as well as psychiatric disorders in children.

One of the day-long seminars covered the complicated and emotionally charged issue of involuntary commitment. J. Rock Johnson, ESQ., a consumer who has two siblings and a parent with mental illness and, in fact comes from a family with mental illness in three generations, spoke eloquently and persuasively against commitment, but cautioned advocates on both sides of the debate to work together and not let this issue divide them. Another participant observered that "involuntary treatment" is like "jumbo shrimp" or "military justice." Ron Diamond, MD, made a compelling case for community care (sounds like CCSS), saying, "Community systems only work if we try them, but if we try them, they do work."

As part of its commitment to family/consumer education and support, the Department sponsored $5,000.00 in scholarships.

ALTERNATIVES '95 Conference

Alternatives, the national consumer/survivor/ex-patient conference was held August 3-6, 1995 in St. Paul, Minnesota. Presented by the National Empowerment Center, its theme was "Returning to our Roots": Rights and Renewal. It focused on the the development and support of consumer leadership to facilitate the growth of consumer run alternatives. Patch Adams, the key-note speaker, discussed "Choosing Joy." The Department sponsored $6,000.00 in scholarships.

Violence and Serious Mental Illness

Is the name of this year's major Fall teaching conference sponsored by the Massachusetts Department of Mental Health, Harvard Medical School and the University of Massachusetts Medical Center, in collaboration with the Massachusetts Psychiatric Society, the Massachusetts Psychological Association, Massachusetts Nurses Association, Massachusetts Chapter of the National Association of Social Workers, McLean Hospital and Mass Mental Health Center.

The conference will take place at the John F. Kennedy Library on September 28-29, 1995. For more information, call Raymond B. Flannery, Ph.D., Director of Training at 617-727-5500 Ext.417.

...From Front Page...

Funded: Experimental Comparison of the PACT and Clubhouse Models

Paul Barreira, M.D., of the University of Massachusetts, Department of Psychiatry is a Co-Investigator and is responsible for supervision of the project implementation at Worcester. The PACT programs will be provided by Community Healthlink CMHC in Massachusetts. The experimental program at this site will consist of multidisciplinary teams experienced in the delivery of community-based mobile services who will be trained to follow the PACT model. The Clubhouse program will be provided by Genesis Club, Inc. Each program in the study will be provided with staff training in their respective model and with funds to staff the vocational rehabilitation components of their program. Assessments of program fidelity to each model will be provided on a yearly basis by representatives of each model who are not involved in training.

Data sources for the project will include consumer self-reports and interviews, staff self-reports, agency records, service logs, and site-visit assessments of the experimental programs. All consumer participants will be interviewed at six month intervals, and monthly self-reports and staff service reports will be obtained through customized computer software. The primary goal of the project will be to determine the relative effectiveness of the two models for increasing consumer competitive employment.

Dear Readers....

The numerous responses to the requests for stigma slaying ideas indicates that a great many people have been thinking about this problem, believe it is important, that it's do-able and that the time is now. One suggestion came from Eileen Murray, a member of the Metro West Area Board: how about a panel discussion among members of organizations who have experienced discrimination and have worked to change perceptions and policy? The NAACP, AARP, Anti-defamation League, NOW, NAMI, all come to mind. There are others. Murray thinks this may be interesting for TV to cover. Could it be a Mental Illness Awareness Week project for your CCSS Board? Please keep your creative juices flowing and the Bulletin will keep you informed.

Along with the enormous amount of studying and planning they have been doing, CCSS Boards and Site Directors are already at work on ideas to make this week a time of education and outreach. **Share your ideas and strategies.**

Ann Madigan

MENTAL ILLNESS AWARENESS WEEK

October 1-7, 1995

More troops are being called to the front in the fight against stigma.....

The National Alliance for the Mentally Ill (NAMI) has announced a multi-year campaign to change the way America views people with severe mental illness. The present sponsors include the pharmaceutical companies Eli Lilly, SmithKline Beecham and Janssen. The National Institute of Mental Health (NIMH) will also be a partner in this effort.

The Schizophrenia Society of Canada has launched its battle-cry:

"SCHIZOPHRENIA:
IF YOU THINK SPELLING IT'S HARD,
IMAGINE LIVING WITH IT."

Solving mysteries, fighting stigma...

..Sherlock Holmes, Nancy Drew, James Bond, Bo Bradley....Bo Bradley?! Yes, Bo Bradley has joined the list of crime investigators extordinaire. Like her counterparts, she is smart and funny and gutsy. Unlike them, Bo Bradley has manic depression. She is the creation of San Diego based author Abigail Padgett whose son has bipolar disorder. *Child of Silence*, *Strawgirl* and *Turtle Baby*, published by a division of Warner Books, features Bradley, a person with mental illness as a <u>solver</u> of crimes, <u>not</u> the perpertrator. The series has won acclaim from reviewers, advocacy groups and its many loyal readers.

Joke Du Jour

Q: How many psychiatrists does it take to change a light bulb?

A: Only one. But it takes a long time and the light bulb really has to want to change.

NAME _____
ADDRESS _____
CITY _____
STATE _____
ZIP _____
TEL _____

Join The CCSS Bulletin?

We hope you have enjoyed reading our Newsletter. We have a database (a sort of computerized telephone book) that allow us in a matter of seconds to retrieve people by specific areas of primary interest. If you aren't already on our mailing list or would like to be included we encourage you to fill this form and return it to us. Confidentiality is assured. We appreciate your interest, time, and enthusiasm.

Would you identify yourself (optional) as:

Consumer☐ Family☐ Provider☐

Please list any specific interest in any of these area of mental illness:

1)☐ Housing
2)☐ Employment
3)☐ Education/Return to school/Supported Education Programs
4)☐ Substance Abuse
5)☐ Medicaid, Medicare
6)☐ Clubhouse
7)☐ Advocacy on State Budget & Legislation
8)☐ Parent of a child with serious emotional disturbances
9)☐ SSI/SSDI
10)☐ Welfare Reform

Briefly Noted...

ROOM for IMPROVEMENT....

San Fransisco - - Many patients with chronic psychiatric disorders who are discharged from state hospitals to structured residential settings improve significantly in cognitive and social functioning and eventually move on to independent living. The work of Dr. Robert Okin, professor of clinical psychiatry at the University of California, School of Medicine, and former Commissioner of the Massachusetts DMH, is the first to examine the long-term outcome of patients discharged after long hospital stays to well-staffed community settings.

Most surprising was the news that those with the lowest level of social functioning improved the most. About 70% of the patients had schizophrenia. Most of the others had schizoaffective, bi-polar disorders or atypical psychosis. Policy makers have commonly believed that the more severe the patients' symptoms and the lower their functioning, the less ready they are for discharge. (Psychiatric Services, January, 1995)

ADOLESCENTS SWAP a "HEALTHY ADDICTION" for SUBSTANCE ABUSE...

Boston - - The best way to treat young people with a substance addiction is to "help them find another religion," said family therapist, Michael Elkin at a meeting on adolescent suicide sponsored by the Cambridge Hospital. Mr. Elkin diverts kids from addictions by steering them toward healthier preoccupations that revolve around learning skills, such as sports. Interacting with others around this new interest is as therapeutic as the swap. Since isolation is the one thing that unites adolescents who are seriously suicidal, you want to help them break their isolation any way you can, Elkin counsels.

HEART ATTACK or PANIC ATTACK?.....

A new ten minute psychiatric questionaire can now help emergency room physicians distinguish patients with panic attack from those with heart attack, according to a report given recently at the Heart Association's 67th Scientific Sessions. About half the people seeking emergency care for chest pain are not recognized by cardiologists as having panic disorder. Improving detection will spare some patients expensive and inappropriate cardiological interventions as well as providing the opportunity to initiate help for this serious and often misunderstood condition. (Primary Psychiatry, Jan., 1995).

Interested in becoming involved in the CCSS planning?

BREAKDOWN OF NATURAL SERVICE AREAS/CCSSs & WHO TO CALL

WESTERN MASS.
James Duffy,
Area Director
413-584-1644
1 Central/South Berkshire
2 Franklin/North Quabbin
3 Hampshire
4 Holyoke/Chicopee
5 North Berkshire
6 Springfield
7 Westfield

NORTH EAST
Lorene Bourque,
Interim Area Director
508-851-7321
1 Beverly
2 Greater Lawrence
3 Greater Lowell
4 Haverhill/Newburyport
5 Lynn
6 Wakefield

METRO WEST
Theodore E. Kirousis,
Area Director
508-792-7400 2073
1 East
2 West

CENTRAL MASS.
Constance Doto,
Area Director
508-752-4681
1 Blackstone Valley
2 Fitchburg/Leominster
3 Gardner
4 South Central
5 Worcester

METRO SOUTH
Barbara A. Leadholm,
Area Director 508-359-7312 ext.600
1 Newton/South Norfolk
2 South Shore/Coastal

SOUTHEAST
John P. Sullivan,
Area Director
508-580-0800 ext. 201
1 Brockton
2 Cape Cod
3 Fall River
4 New Bedford
5 Plymouth
6 Taunton/Attleboro

METRO-BOSTON
Clifford Robinson,
Area Director
617-727-4923 ext. 301
1 Bay Cove
2 Cambridge/Somerville
3 Lindemann
4 Mass. Mental Health Center
5 Solomon Carter Fuller

The CCSS Bullettin
c/o DMH
25 Staniford St.
Boston Ma. 02114

RETURN TO SENDER

GONE

Statehouse
Rep. Raymond [redacted]ordan, Jr.
Beacon Hi[redacted]
Boston[redacted] 02133

Please
Recycle
This Newsletter

The CCSS Bulletin

A publication for citizen participation in the Comprehensive Community Support System

Massachusetts Department of Mental Health Vol.1 No 3 Nov. 1995

Medicaid and Managed Care

Between 1987 and 1992 the number of states adopting a managed care approach within their Medicaid program doubled, and doubled again between 1992 and 1994. Today, 44 states operate one or more managed care programs for their Medicaid population, covering 8 million beneficiaries, or approximately 24% of all Medicaid enrollees.

On September 22nd, 1995 the Massachusetts Division of Medical Assistance (DMA) released a Request for Proposal (RFP) for the rebid of its mental health and substance abuse managed care plan, currently carried out by Mental Health Management of America (MHMA). The contract will include acute inpatient hospitalization and emergency services presently contracted by and for the Department of Mental Health. Historically, people with mental illness have received different types of acute inpatient care depending upon their type of health coverage (i.e. DMH beds vs. MHMA beds). The joint purchasing initiative is designed to strengthen both acute and continuing care services by expanding the provider network, and ensuring a one-tier, seamless delivery service system.

This new contract with a Managed Care Organization (MCO) will be expanded to include coverage for an increased number of people in need of mental health care, who previously received care through the free care funding. Currently, the DMA Mental Health Substance Abuse Plan covers a large number of Medicaid recipients and has been administered by MHMA since 1992, when Massachusetts received permission from the federal government to place recipients in managed care plans.

As part of the new collaboration between DMH and DMA, DMH is handing the operation aspects of its acute care to DMA. Together the two agencies will be responsible for contracting and monitoring the Managed Care Organization (MCO). In addition, DMH shall have the responsibility for developing annual individual CCSS plans. Citizen participation in the planning and monitoring of services remains an important component of this interagency effort since the agreement provides that DMH shall work with DMA and the MCO to implement the recommendations of the CCSS plans in the

(From Previous Column)

acute and continuing care system.

Presently, Massachusetts has received permission from the Health Care Financing Administration (HCFA) To develop Medicaid managed care programs and offer the uninsured new opportunities to be "publicly insured." This five-year permission, was granted in the form of a "waiver": Section 1115 Research and Demonstration Medicaid Waiver, and is pending enactment by the Massachusetts Legislature.

(Continues to Page 2)

Governor Weld's Plan to Restructure Government

proposes integrating the existing 14 human service agencies into four new departments which would operate under the new department called "Public Health Services." This plan calls for sweeping changes in the present system and will require thoughtful and extensive review. As information becomes available the CCSS Bulletin will keep you informed. Meanwhile, if you would like to receive a copy of the proposed plans for restructuring government call Pam at 1-800-221-0053.

The Role of the DMH Constituents:

Clarifying Existing Guidelines for:

CCSS Advisory Boards, Area Boards and Statewide Advisory Council.

A task force has been appointed in response to the required work plan for a corrective action regarding the DMH Citizen Participatory in the DMH service planning activities. The purpose of the task force will be to draft clarifying guidelines regarding the role of the DMH CCSS Advisory Boards, Area Boards and Statewide Advisory Council (SAC).

(Continues to Page 3)

Inside This Issue:

What is section 1115 Waiver?

Section 1115 (known as "eleven fifteen") of the Social Security Act gives HCFA authority to waive specific requirements of the Act, to help test new policy approaches that are consistent with the overall objectives of the Medicaid program. The 1115 waiver must be consistent with HCFA goals, but may test alternatives to HCFA policies. Section 1115 allows the state to be exempted of current federal requirements and regulations in order to expand Medicaid coverage to uninsured individuals and families, by the development of managed care plans. Demonstration waivers last typically five years, according to HCFA rules. If the demonstration approach proves successful, a waiver may be extended until statutory changes are made, to make the demonstration approach permanent.

Medicaid Block Grants (MediGrants)

Gaining control over burgeoning state Medicaid budgets has been a perennial pastime of the spring session for most state legislatures. But this year the game has an entirely new set of rules.

Congress is considering several proposals that would change dramatically the Medicaid program. Most of the proposals would transform Medicaid into a block grant, end the program's individual entitlement which guarantees benefits to anyone that meets the eligibility criteria, and place a cap on annual growth of federal spending. Through this process, states would get more flexibility to run their programs through relief from many federal rules and regulations. But the consensus ends there. Officials at both levels of government are divided over how much flexibility states should have, whether states should be entitled to extra funds if they run into hard economic times, and whether certain groups of people should be eligible in all states.

The prospect of Medicaid becoming a block grant raises numerous issues for state governments: How exactly would they work?

- *How would it effect spending variations that already exists among states?*
- *How will state deal with their inability to rely on automatic government funding increases at a time when the number of uninsured is on the rise?*
- *How would state live within the suggested set percent growth rate?*
- *Will this new design provide mean that state could cover more-or possibly less-of the low income population than they can under the current Medicaid program?*
- *With block grants, no longer would the joint federal and state-funded Medicaid program be an individual entitlement. Instead, states would receive one capped sum from the federal government, which would likely be based on projected enrollment under the current rules.*

One of the most difficult issue to resolve in deciding how to implement block grants is the current disparity among states in Medicaid spending. Currently for every dollar that a state provides toward Medicaid services, the federal government provides $1 to $4 in matching dollars, varying intensely with each state's average per capita income. Medicaid spending per poor person tends to be greater in high income states compared to low income states. Since states have some control over how much they spend, many of the high income states bring more federal funds than the average, despite their lower federal match rate.

Some states would try using managed care and other strategies to make up for the loss of federal funds. But if they can't or won't, some states would need to increase state spending to maintain current benefits, eligibility and reimbursement levels. The task would be very difficult and these states would likely be faced with a reduction of services.

CCSS-BULLETIN MISSION and VISION

As the Department of Mental Health moves into the next chapter in the development of a Public Managed Care system, we must affirm our commitment to the importance of constituent participation and to the Comprehensive Community Support System (CCSS) model. We must also acknowledge that committment and good training are critical to the effectiveness of participation and to realization of the vision of the Comprehensive Community Support System. Each month this bulletin will provide you the "news you can use" to inform and educate you about citizen participation and development.

We are interested in your ideas:

Write to us:
"The CCSS Bulletin"
Co-Editors: Tony Pizzuti
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Send us a Fax at:
617-727-5500 ext. 375
Send us E-Mail at:
tpizzuti@state.ma.us or
amadigan@state.ma.us

(Continues from Page 1)

The guidelines, when completed, will become an addendum to the DMH Handbook for advisory boards. The clarifying guidelines will not cover issues already addressed in DMH regulations and the DMH Handbook relative to advisory boards. Rather, it is expected that the guidelines will seek to illuminate the following issues relative to the advisory role of these volunteer boards:
Concept of "advisory": a discussion of:

- *what the concept means in practical terms,*
- *what boards can do to enhance and make meaningful their role as advisors to DMH, what is the authority, and inherent limitations, of boards which are advisory,*
- *how this authority may differ from other boards - e.g., the authority of the board of directors of a corporation,*
- *how this advisory role differs from the role of management, and*
- *how DMH can seek to ensure that advisory boards have the resources, information and skills to play a meaningful advisory role in the planning and delivery of services for mentally ill persons - e.g., training, what kinds of information is shared with boards, and recruitment of new members.*

Relationships of (and between) advisory boards: a discussion of:

- *the advisory relationship between the CCSS Boards and the Area Boards,*
- *the relationship between these boards and the SAC,*
- *the advisory relationship between subcommittees of a Board, including but not limited to the ad hoc CCSS Planning Committees, and the Board itself,*
- *the role of non-appointed members of subcommittees, and*
- *the relationship of these advisory boards to other persons, programs and functions within DMH.*

It is anticipated that the draft prepared by the task force will be shared with DMH staff (including Area Directors and the DMH Policy and Planning Committee) and persons outside DMH (including the CCSS Advisory Boards, Area Boards and SAC) for their input prior to a final draft being prepared and recommended to the Commissioner.

"The way to do things is to begin."
Horace Greeley

DMH/MCDHH Task Force...

...Subcommittee on Deaf, or Hard of Hearing CCSS Planning ...

Over the past year, Commissioner Eileen Elias of DMH and Commissioner Barbara Jean Wood of the Commission for the Deaf and Hard of Hearing, have been meeting with a Steering Committee comprised of field representatives from both agencies. The focus of the meetings has been to address the dual needs of consumers who are deaf, or hard of hearing and seek equal access to mental health services. One subcommittee has been considering the needs of these consumers as they relate to the CCSS planning process.
"A primary aspect of their discussions revolved around communication accessibility for persons who are deaf, or hard of hearing. Accessibility is achieved through the provision of special assistive technology, specialized services (e.g., clinicians and case managers fluent in American Sign Language, interpreters, etc.) and specialized statewide or regional programs (i.e. MCDHH)." Given the CCSS planning process underway, the subcommittee is recommending a two-pronged strategy to enhance communication accessibility in services. The first goal is to increase understanding of the special needs of deaf, and hard of hearing consumers. Use of the Communication Features list included in the last section of the 'green book' (Developing a CCSS Guidance Manual for Area Participatory Planning, March, 1992) will be helpful. Some CCSSs have assigned case managers to specialize in working with this group by developing knowledge of the range of communication needs; learning how hearing loss can impact diagnosis and treatment; and becoming fluent in American Sign Language. These case managers can serve as a resource to the CCSS. The second, longer range goal is to bring the expertise of consumers who are deaf, and hard of hearing as well as specialized service providers or "consultants" to the CCSS to assist in overall planning for this consumer population. Such a local task force or ad hoc group could address the issue of increasing the participation of this consumer population in the CCSS planning process. The group could also explore local needs, regionalization of services, interagency collaboration, resource allocation and specialized planning at the CCSS level. The development of such a constituent group will ensure that the needs of the consumers will be considered in the development of further CCSS plans. We must ensure that the above stated goals are incorporated into the CCSS planning process.

Learning Opportunities...

CONFERENCES and FORUMS... John Fitzgerald Kennedy Library Boston, MA.

CONFERENCE on VIOLENCE and MENTAL ILLNESS, held on September 28-29, 1995 examined the connection between mental illness and violence,with presentations from clinicians, researchers, forensic experts, educators,family members and consumers.

Paul S. Appelbaum, M.D., Chair of the Department of Psychiatry and Professor of Psychiatry at the University of Massachusetts Medical Center, started the conference off by challenging the common wisdom, that the mentally ill are no more violent than any other group of people, noting that the public at large never believed that in the first place. Prudence Baxter, M.D.,who is a Forensic Mental Health Supervisor for the Department of Mental Health and Clinical Instructor in Psychiatry, Harvard Medical School, calls this a case of research catching up with common sense. She says that "violent" is a term so broad as to be almost useless: "does it mean to kick the TV, or shoot with an Uzi?"

Research now suggests a clear link between some forms of mental disorder and a propensity for violence. However, Dr. Appelbaum pointed out that this is a relatively small component, nowhere near as large as the effects of age, gender and education. As for safety on the streets, he proposes that it would be far better to pay attention to young people, especially males who use drugs and alcohol.

Dr. Appelbaum, whose most recent book is *Almost a Revolution: Mental Health Law and the Limits of Change*, hopes that rethinking the relationship between mental illness and violence will "encourage the funding of desperately needed outpatient and post-hospitaization services and provide motivation for channeling new resources into psychiatric research."

This annual conference was one of a series undertaken by the Department of Mental Health which underwrote the cost of the program as part of its commitment to the training of its state and provider workforce.

"Home of Your Own" Program:

by Kathryn McHugh

Massachusetts was recently awarded a National Home Of Your Own Technical Assistance Grant. This grant is part of a five year agreement from the federal Administration on Developmental Disabilities and Health and Human Services to create a national information and technical assistance center on person-controlled housing, home ownership and personalized supports for people with disabilities. Over a five year period, a total of 23 states will be selected to receive technical grants.

The Massachusetts Home of Your Own Program will be administered by the Citizens' Housing and Planning Association (CHAPA). CHAPA submitted the application in collaboration with the Department of Mental Health, the Department of Mental Retardation and the Massachusetts Rehabilitation Commission.

This grant will provide technical assistance over a three year period which will:

- *expand homeownership opportunities and increase control over the living environment of people with disabilities*
- *educate consumers, providers, family members, state agencies, lenders and others about available community based housing options*
- *increase the capacity of consumer organizations, non profit groups and others to expand innovative housing options and advocacy opportunities to people with disabilities*
- *improve the coordination of existing housing resources and support services for people with disabilities*

Although we have received notification of the award we have not yet received the funding. Part of the grant will be used to establish an 800 number at CHAPA to respond to requests for information and to receive names for the mailing list. Individuals will receive information on trainings and conferences which will identify people for the homeownership program. The Bulletin will provide you with further information including a 1-800 number when it becomes available so you can find out more.

The following letter, accompanied by the NAMI booklet "Information for Writers," was sent to newspaper editors across the state. Response to it has been instructive: a Western Massachusetts newspaper called it "shades of Monty Python's Ministry of Silly Walks" under the heading, "State Thought Police." A reporter for a news daily in Lynn suggested that the anti-stigma coordinator be described as "wacko" or "nuts' and belonged in the "looney bin." On the other hand, the Clinton Daily Item's staff writer, Ann Mazzola did a feature piece on stigma which expanded on the points made in the letter.

All of this proves the case, that stigma is real, that ignorance abounds and that this campaign has work to do.

HARD to BELIEVE.....

"I thought we were beyond this, that it was terminology we thought had disappeared," said Peg Aho about the graffiti spray-painted on the building of West Winds Club in Fitchburg. West Winds provides training, support and a social center for people diagnosed with a mental illness.

Aho is one of 80 members who were shocked and hurt to find "nut house" and "crazy ones" painted on the walls of the club. She said that the graffiti showed that "whoever wrote it doesn't understand what it is to have mental illness."..... .....And how about the Halloween Scream shop in the Meadow Glen Mall in Medford which featured a costume that said, "Property of State Mental Hospital, including a scarey mask?. And imagine. This was seen in the store window during Mental Illness Awareness Week!

Name of Editor
Every Newspaper
00 Address Street
City, MA 00000

August 25, 1995

Dear Editor,

The Department of Mental Health has undertaken a campaign to confront and erase the discrimination that envelops mental illness.

Severe mental illness afflicts more than 31 million Americans. Twenty-five percent of all hospital beds are filled by mentally ill patients - more beds than those occupied by people with heart disease, cancer and respiratory ailments combined. The stigma of mental illnesses is pervasive, affecting housing, educational and job opportunities, research funding and available care. It often prevents people from even seeking treatment.

Our goal is to end the exploitation of people with mental illness for humor or sensationalism. We ask that your editorial policy encourage portrayals of people with mental illness as human beings, not caricatures and promote the accurate use of medical terms associated with psychiatric disabilities. The misuse of "schizophrenic" to mean split personality is a good example.

"At a time of growing sensitivity to racist and sexist language, no such caution governs the use of the vocabulary of mental illness..."
TIME, Feb., 1993

This is, however, more than a simple plea for the careful use of language. It is a call for a change in public attitudes that can lead to enlightened public policy which, in turn, will create the will to provide the finest treatment and eventually find cures for these dreaded, disabling disorders.

Please join us in this task.

Sincerely,

Ann Madigan
Anti-stigma Coordinator
enclosure

Briefly Noted...

"Gladly would he learn and gladly teach."

This quotation from Chaucer is how Bostonia Magazine (Fall,1995) describes Solomon Fuller Carter, who at age ten was reading Julius Caesar in Latin.

In 1882 in his native Monrovia his abilities and interests always suggested a boy of uncommon promise. By 1897 he had graduated from Boston University School of Medicine and fulfilled his youthful promise by distinguishing himself as a neurologist and student of mental illness.

When we hear his name today it is the Solomon Carter Fuller Mental Health Center in Boston's South End which comes to mind. He is not so widely known as "the first African-American psychiatrist", which he was.

The Center for Psychiatric Rehabilitation at Boston University

has been designated as a Collaborating Center by the Mental Health Division of the World Health Organization (WHO), one of just four such centers in mental health in the world and the only one in this country.

Zoning Laws Can't Be Used To Ban Group Homes....

The Supreme Court has handed down a decision that is a victory for people with mental and physical disabilities, holding that municipalities cannot use zoning laws to exclude group homes from single family residential areas. In a 6-3 decision, Judge Ruth Bader-Ginsberg, writing for the majority, said that zoning ordinances which restrict occupancy based on family composition could not be used to discriminate against disabled individuals residing in group housing.

Double Jeopardy: Person with Mental Illness in the Criminal Justice System,

a report issued to Congress by the Center for Mental Health Services (CMHS) provides "core principles" for mental health, law enforcement and correction personnel. It recommends:

- better coordination among criminal justice, juvenile justice, mental health, substance abuse, housing, educational, vocational and HIV/AIDS treatment programs
- more creative use of existing resources
- an increased focus on people who have both a mental illness and a substance abuse disorder
- cross-training of mental health, law enforcement and correction personnel
- culturally appropriate services for African American, Hispanics and other minorities
- better understanding of the criminal justice system demands and constraints
- reduced diagnosis and treatment costs through broad dissemination of new knowledge about what works and what does not.

As our society gets tough on crime, it is essential that we are able to provide diagnostic and treatment services as soon as individuals with mental disorders encounter the criminal justice system.

We know that treatment for mental illnesses has a greater success rate than treatment for heart disease. We also know that many individuals end up in the criminal justice system who are ill not criminal. Regarding the issue of people with mental illness that end up in jail, Bernard Arons, M.D. Director for Mental Health Services of the U.S. Department of Health and Human Services said "...they need to be diverted to appropriate treatment programs where they can receive the support they need to thrive and succeed in society."

PUBLICATION...A call for Submission:

The Journal *Hospital and Community Psychiatry* is seeking first-person accounts of consumers' experiences with mental illness for a column scheduled to debut this year.

Submissions of up to 1,600 words should be addressed to Jeffrey L. Geller, M.D., editor of the "First Person Accounts" column.

Send manuscripts to him at the Department of Psychiatry, University of Massachusetts Medical School, 55 Lake Ave. N., Worcester, MA 01655. *Unused material will be returned.*

"Happiness is the wish to be what you are."
Erasmus

GLOSSARY of MANAGED CARE

Access: The ability to obtain desired health care. Access is more than having insurance coverage or the ability to pay for services, but is also determined by the availability of services, acceptability of services, cultural appropriateness, location, hours of operation, transportation, and cost.

Admission Certification: A form of utilization review in which an assessment is made of the medical necessity of a patient's admission to a hospital or other inpatient institution, to assure that such care is needed. Lengths of stay appropriate for the patient's diagnosis are usually assigned, and payment by any program requiring certification is assured. Certification can be done before admission (pre-admission) or shortly after (concurrent).

AFDC: Aid to Families with Dependent Children. Children who Quality for AFDC also receive Medicaid benefits.

Ambulatory Care Facility: A facility that provides health care service (such as surgery) on an outpatient basis, meaning an individual does not have to stay overnight. Most inpatient facilities (such as hospitals), also offer ambulatory services. Ambulatory is sometimes called outpatient.

Ancillary Services: Laboratory tests, x-rays and all other hospital services other than room, board and nursing service

Back-filling: The process of restoring utilization of beds or placements in a residential facility after occupancy has been reduced and the freed-up resources reallocated. Example: Agency A reduces its use of the state hospital through funding obtained by decreased utilization, and Agency B "back-fills" the recently vacated beds with new admissions.

Beneficiary: A person currently eligible to participate in the social insurance programs that do not use means tests, such as Medicare Part A and SSDI.

Capitation: A method of financing health care services that provides a fixed, per-person, amount that a health provider/provider organization is paid for a given time period (usually a year), regardless of the amount of services provided, but with expected client outcomes. Capitation involves shared risk and rewards between the payor and the provider that encourages provider flexibility in achieving outcomes. Capitation is used in progressive mental health community support systems as a way to optimize care access, responsiveness, quality, and cost management (See also Full Capitation and Partial Capitation.)

Carve-out: A program delivery and financing design wherein a state or other finder arranges services for a certain population (such as persons with serious mental illness) through distinct and separate service organizations, such as community mental health centers, or though specialized networks of mental health service providers. The carve-out is typically worked out through separate contracting or subcontracting for services to the special population.

Case Management: a system embraced by employers and insurance companies to ensure that individuals receive appropriate, reasonable health care services. [In Massachusetts DHM case management is a state-run service based on a linkage or "broker" model.]

Categorical Eligibility: in Medicaid, indicates persons who are certified eligible by class, or "category", rather than individually, when individually meeting the entry requirements and being enrolled in one program automatically qualifies the recipient for another program. SSDI beneficiaries are categorically eligible for Medicare after 24 months; SSI recipients are categorically eligible for Medicaid in most, but not all, states. Medicare beneficiaries with income below the poverty line and assets at twice the SSI threshold are categorically eligible for Medicaid.

Claim: A request by an individual (or his or her provider to an individual's insurance company for the insurance company to pay for services obtained from a health care professional.

Many of the terms used in this glossary are from A Glossary of Insurance Terms by "Mental Illness & Managed Care a Primer for Families and Consumers.

Name_____
Address _____
City _____
State_____
ZIP_____
Telephone ( ) _____

Would you identify yourself (optional) as:

☐ Consumer ☐ Family ☐ Provider

Please list any specific interest in any of these area of mental illness:

1) ☐ Housing
2) ☐ Employment
3) ☐ Education/Return to School/Supported Education Programs
4) ☐ Substance Abuse

Join The CCSS Bulletin?

We hope you have enjoyed reading our Newsletter. We have a database (a sort of computerized telephone book) that allow us in a matter of seconds to retrieve people by specific areas of primary interest. If you aren't already on our mailing list or would like to be included we encourage you to fill this form and return it to us. Confidentiality is assured. We appreciate your interest, time, and enthusiasm.

5) ☐ Medicaid, Medicare
6) ☐ Clubhouse
7) ☐ Advocacy on State Budget & Legislation
8) ☐ Parent of a child with serious emotional disturbances
9) ☐ SSI/SSDI
10) ☐ Welfare Reform

Interested in becoming involved in the CCSS planning?

BREAKDOWN OF NATURAL SERVICE AREAS/CCSSs & WHO TO CALL

WESTERN MASS.
James Duffy,
Area Director
413-584-1644
1 Central/South Berkshire
2 Franklin/North Quabbin
3 Hampshire
4 Holyoke/Chicopee
5 North Berkshire
6 Springfield
7 Westfield

NORTH EAST
Lorene Bourque,
Interim Area Director
508-851-7321
1 Beverly
2 Greater Lawrence
3 Greater Lowell
4 Haverhill/Newburyport
5 Lynn
6 Wakefield

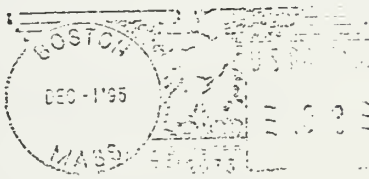
METRO WEST
Theodore E. Kirousis,
Area Director
508-792-7400 2073
1 East
2 West

CENTRAL MASS.
Constance P. Doto,
Area Director
508-752-4681 Ext. 263
1 Milford
2 Southbridge
3 Gardner
4 Fitchburg
5 Worcester

METRO SOUTH
Barbara A. Leadholm,
Area Director 508-359-7312
ext.600
1 Newton/South Norfolk
2 South Shore/Coastal

SOUTHEAST
John P. Sullivan,
Area Director
508-580-0800 ext. 201
1 Brockton
2 Cape Cod
3 Fall River
4 New Bedford
5 Plymouth
6 Taunton/Attleboro

METRO-BOSTON
Clifford Robinson,
Area Director
617-727-4923 ext. 301
1 Bay Cove
2 Cambridge/Somerville
3 Lindemann
4 Mass. Mental Health Center
5 Solomon Carter Fuller



The CCSS Bulletin
c/o DMH
25 Staniford St.
Boston Ma. 02114

The CCSS Bulletin

A publication for citizen participation in the Comprehensive Community Support System

Massachusetts Department of Mental Health Vol.1 No 4 Feb. 1996

Interview With Commisioner Elias

Elieen Elias is leaving DMH February 21,1996, nearly five years after assuming responsibilitiy as Commissioner. She is looking forward to spending more time with her family and will be "consulting in health care delivery, policy development, and technical assistance, nationally and internationally." Her decision to leave came after a two-week stay in Israel, where she is considering work as a technical consultant, as that country's health care delivery systems move toward a managed care model.

Reflecting on her work, Elias reminisced about the early years of her career and her very first job at a clubhouse in Philadelphia. It was at Horizon House, while doing quality assurance, that she became committed to the importance of consumer empowerment. She attributes being a "first generation American, the impact of the Holocaust, and the influence of her mentor, Armin Lob, whom Elias calls a visionary, to her desire to make changes that would improve the lives of people with mental illness.

"The fact was that I couldn't do it alone. It was a partnership where I brought staff from both the private and public sectors that understood the restructuring needs, the centrality of the consumer and the importance of the CCSS. I am very proud of it and the way everybody worked together to make the changes we did."

The Commissioner is confident that Marylou Sudders, the state's new mental health commissioner will espouse the same values and will bring a new perspective to the current challenges.

Marylou Sudders takes the reigns as Commissioner on February 22nd. We hope to have an interview with Commissioner Sudders for the next issuse.

Inside This Issue:

Massachusetts Client-Mortality Study Reveals a National Problem

After the report of an increase in deaths among its clients, the Massachusetts Department of Mental Health requested an independent Task Force to review the reporting and interpretation of DMH data on client deaths. Between August and November, 1995, this group met six times. The Evaluation Center at the Human Services Research Institute in Cambridge, Mass. provided technical assistance with funding from the federal Center for Mental Health Services (CMHS). It concluded that the death rate among Massachusetts DMH consumers had decreased from 1991-1993.

What it also found was a serious, nationwide problem, that persons with serious mental illness die 10-15 years earlier on average than the general population and that the common causes of death are cardiovascular and respiratory diseases as well as chronic illnesses such as diabetes, not accidents and suicides, as is commonly thought.

This information has signifigant implications for the entire mental health field. Although it has long been known that people with mental illness have serious medical problems, H. Stephen Leff, Ph.D., coordinator of the study and director of of the Evaluation Center, says, "We in the mental health movement have not attended to this as much as we should have."

The Task Force isssued 38 recommendations to DMH on how mental health care and and general health services need to be linked, which is precisely one of the goals of the Comprehensive Community Support System (CCSS).

Noting that mental illness itself, can be viewed as a risk factor for mortality through medical disease, some of the problem areas identified were:

- ***The frequent presence of alcoholism and drug addiction and the need to to take active steps to help clients recover from addiction***
- ***Attention to the physical health problems associated with psychotropic medications***
- ***Poor health habits and behaviors which are often found in the DMH population***
- ***Smoking as the clearest example of a life-threatening behavior which is over represented among people with mental illness***

The findings of this report present challenges and opportunities for the Department of Mental Health, the entire health care industry and to society. Dr. Leff envisions the time when mortality rates due to physical causes will be one of the most important indicators of performance on the part of providers.

The "Report on Massachusetts Department of Mental Health Service Recipient Mortality (1991-1993)" is available from the Evaluation Center for the cost of reproduction.

Call David Hughes at 617-876-0426.

Restructuring Government....

GOVERNOR WELD'S RESTRUCTURING PROPOSAL SUMMARY

Governor's Weld's Budget for FY'97 (House I) support the plans released on November 1, 1995 for reorganized state government currently composed of five Cabinet Secretariats and 74 Operating Agencies.

This restructuring proposal of course pertains all of the state agencies in the Commonwealth - but in this Bulletin, we will primarely focus on proposed changes in the human services side of it. The plans call for the current Executive Office of Health and Human Services (EOHHS) to be renamed Family Services, and to consolidate the existing 16 agencies into four separate divisions: 1) Children's Services, 2) Rehabilitative Services, 3) Transitional Assistance and 4) Public Health Services.

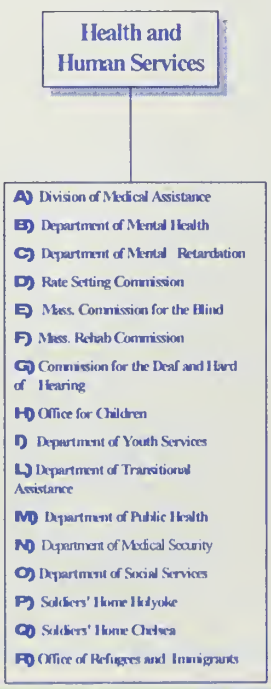
The Department of Mental Health would be consolidated under the new Department of Public Health Services which will also include the current Department of Public Health, the Division of Medical Assistance, the Division of Medical Security, and the Rate Setting Commission.

The proposed mission statement for the new DPHS follows:

The Department of Public Health Services (DPHS) promotes and assures conditions and activities that improve aud protect the health of Massachusetts residents. DPHS focuses on coordination of care aud community status of individuals, families and communities. It supports programs which prevent and treat diseases and disability, intervenes to reduce public health threats and assists families and individuals in obtainiug high quality, appropriate health services. DPHS provides health services to those at highest risk and greater need, including those with serious psychiatric illnesses, in a manner which stresses integration of disease prevention, treatment and rehabilitation. DPHS encourages the highest individual level of functionality and self-sufficiency while ensuring the long term care and protection of those who require it.

Population Served by DPHS:

- *The financially needy without insurance or underinsured; families, children, disabled, elders, unemployed adults.*
- *Seriously and persistently mentally ill adults and seriously emotionally disturbed children.*
- *Troubled, at risk children and adolescent.*
- *Pregnant women and infants.*
- *Health risk groups; e.g., AIDS/ IIIV, IV drug users, homeless, STDs, victims of sexual and domestic violence.*
- *The Public - for public health education and safety services.*
- *State employees and retirees (as purchaser of health insurance)*



CCSS-BULLETIN

MISSION and VISION

As the Department of Mental Health moves into the next chapter in the development of a Public Managed Care system, we must affirm our commitment to the importance of constituent participation and to the Comprehensive Community Support System (CCSS) model. We must also acknowledge that committment and good training are critical to the effectiveness of participation and to realization of the vision of the Comprehensive Community Support System. Each month this bulletin will provide you the "news you can use" to inform and educate you about citizen participation and development.

We are interested in your ideas:

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"The CCSS Bulletin"
Co-Editors: Tony Pizzuti
Ann Madigan
Department of Mental Health
25 Staniford Street, Boston, Ma. 02114

Send us a Fax at:
617-727-5500 ext. 375

Send us E-Mail at:
tpizzuti@state.ma.us or
amadigan@state.ma.us

DPHS PROGRAM COMPONENTS

a) Division of Health Maintenance and Prevention

b) Division of Purchased Health Services

c) Division of Health Policy Research and Planning

FY '97 DMH House 1 Budget Facts

In FY' 97, the DMH Budget received base cuts and then funding was added to either expand certain services or cover historical deficiencies.

Base Cuts: $21,600,000 M

1) $11,500,000 Reduction in the state facility appropriation

Explanation: There is an assumption that the state hospitals and CMHCs can achieve certain efficiencies by changing the way they do business or finding ways to become more competitive in the marketplace.

Impact: DMH will need to develop a strategy to meet this target. Much has already been done to make the state hospitals as efficient as possible given their size. CMHCs may be able to identify more efficiencies. Ultimately, there could be a reduction in the number of facilities (not beds) in order to meet the targeted reduction if funding is not restored.

2) $ 4,000,000 Reduction in the Outpatient services

Explanation: This reduction assumes that the Medigrant (block grant of Medicaid) occurs and that there will be expanded eligibility for Medicaid by persons who currently have no medical coverage. Currently, DMH pays for outpatient services for uninsured persons.

Impact: If Medigrant does not pass, then individual consumers will lose their outpatient care. This funding would need to be restored if the Medigrant does not become a reality. Even if Medigrant passes, consumers currently reimbursed by DMH may lose funding because they still do not qualify under the new income guidelines.

3) $ 6,100,000 Reduction in Administration to be achieved from restructuring of state government. (This is the DMH share).

Explanation: The governor's plan to restructure government made assumptions that administrative staff could be reduced due to various efficiencies which could be achieved if government could be restructured. This staff reduction will affect the Central Office, the Area Offices and the site offices. Approximately 145 FTEs will be affected.

Impact: If restructuring does not occur, this reduction will not be able to be achieved and the DMH will be severely impaired in its ability to carry out its day to day management and oversight functions. Even if restructuring does occur, the DMH share of cuts will have a severe impact upon the DMH field structure which may be too dramatic.

Funding Increases: $14,042,000 M

4) $ 5,500,000 Metro Boston Deficiency funding

Explanation: Funds the deficiency in Metro Boston which will prevent further redirection of resources from other Areas to address the problem.

5) $ 535,000 Child/Adolescent shortfalls and enhanced respite.

Explanation: Covers shortfalls in the C/A account related to Dept. of Education reductions affecting those programs with an educational component. Covers increased physician and nurse on call services for IRTPs and enhances respite services.

6) $ 585,000 Collaborative Assessment Program (CAP)

Explanation: Funds the expansion of the interagency (DSS/DMH/DMA) CAP program from its current pilot in Southeast to all Areas across the state.

7) $ 545,000 Forensic Expansion.

Explanation: Expands services for mentally ill consumers in county correctional facilities and creates a case management service for those returning to the community from prisons and county correctional facilities.

8) $ 2,800,000 Provider Of Service Salary Enhancement for Direct Care Titles.

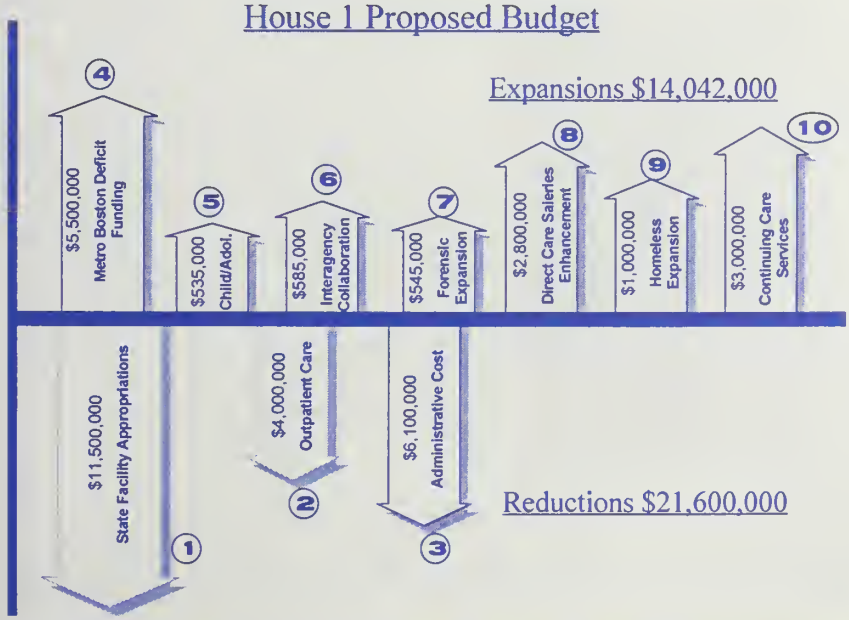
Explanation: Funds a 4% salary adjustment for direct care personnel in contracted programs earning less than $20K.

9) $ 1,000,000 Homeless Expansion

Explanation: Expands residential and support services for the homeless mentally ill.

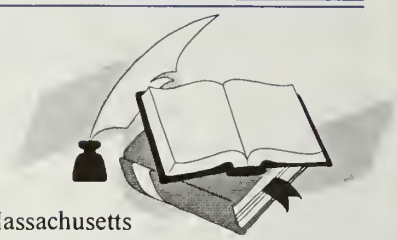
10) $ 3,000,000 Continuing Care Services Expansion

Explanation: Funds the expansion of community services for persons "stuck" in hospitals who need community services in order to be placed.



Learning Opportunities..

CONFERENCES and FORUMS... Housing Opportunities for Consumers



A conference on Promoting Housing Opportunities for People with Mental Illness was held at Holy Cross College, Worcester, MA on December 1, 1995. It was sponsored by the Office of Health and Human Services, the Office of Communities and Development, the Department of Mental Health, the Massachusetts Municipal Association and the Massachusetts Association for Mental Health. It brought together people from the profit and non-profit sectors, government agencies, providers and developers to assess the changing climate in housing, what one speaker called a "revolution, a major reinvention of public housing." Two themes emerged: that housing is "not about bricks and mortar, but about people" and that success depends on dialogue and partnership at the local level.

Valerie Fletcher, Deputy Commissioner, DMH, underscored that need, citing the solid values of the Comprehensive Community Support System (CCSS) which acknowledge that all facets of a person's life are impacted by mental illness. The CCSS is designed to link people locally, with support and rehabilitation services as well as housing.

COMING UP: The Massachusetts Home of Your Own Alliance, of which DMH is a member, will be hosting a conference to promote home ownership and resident control for people with disabilities. It will be held Thursday, June 6, 1996, 9:00A.M. - 4:00 P.M. at the Crowne Plaza Hotel in Worcester. This all-day conference will feature as Keynote speaker, Valerie Bradley of the President's Commission on Mental Retardation and as Lunch speaker, Joy Horvath, Manager of Special Needs Housing, Fannie Mae.

Workshops will include:

- Creative Financing of Home Ownership
- Coordinating Supports and Services
- The Nuts and Bolts of Homeownership
- Innovative Development Projects
- Consumer Control in Supported Housing

A brochure with a registration form will be sent five weeks before the conference. To request a brochure, call Citizens' Housing and Planning Association at (617) 742-0820 after May 1.

Citizen Residential Monitoring Handbook Nears Completion.....

In the spring of 1995, the DMH State Advisory Council (SAC) established a statewide subcommittee or consumers, board members, staff and advocates to develop a program for citizen participation in the monitoring of the Department's residential programs for children, adolescents and adults.

Under the guidance of co-chairs Alan Greene (Metro West) and Barbara Flory (North East), members of the sub-committee designed the framework for how the program would operate in accordance with SAC approved guidelines. The draft Monitoring Handbook: Consumer Satisfaction with Residential Programs is the resultant product.

The current handbook is focused on the monitoring of adult residential programs. Standards for monitoring child/adolescent residential programs is being developed for review by mental health professionals and stakeholders. Once complete, this selection also will be incorporated into the handbook.

Comments on the handbook were solicited from members of SAC, presidents of area and local advisory boards, the consumer council, area directors, site directors, and a group of providers. These comments were extremely helpful in identifying issues that needed further consideration.

After an evaluation of the Monitoring Handbook is completed by the DMH Policy and Planning Committee, it will be presented to SAC for final approval.

Consumers, board members and other interested citizens are encouraged to participate in the monitoring program. All monitors will be required to attend a training prior to monitoring any residential program. Monitor training is expected to be offered by the fall of 1996.

Additional information on SAC's citizen monitoring program can be obtained by contacting Connie Peters, Operations Director, at (617) 727-5500, extension 416.

"Words are, of course, the most powerful drug used by mankind."

Rudyard Kipling

Quote Kipling the next time someone suggests that you "lighten up" about the misuse of the word schizophrenia or when you cringe at the notion of a straight jacket as a joke. Remember that the stigma battlefield is littered with casualties from other anti-discrimination campaigns , those waged by women, minorities, disabled people, ethnic and religious groups. These in turn spawned appropriate and respectful terms as replacements. Now the 20 plus daily talk shows as sources of egregious misinformation and psychobabble have been targeted by practicing psychologist Jeanne Albronda Heaton and her colleague Nona Leigh Wilson, an assistant professor of counselling and human resource development, in their new book, *Tuning in Trouble: Talk TV's Destructive Impact on Mental Health (Jossy-Bass, Inc.).*

The field of psychiatry and those who use its services still struggle with the language of these illnesses, their treatments and their outcomes. There have been no words for the pain of what was once unmentionable. But that is changing and while we refine the words, we sharpen our thinking. "Consumer?" "Neurobiological disorders?" "Care giver?" "Treater?" Even the use of "mental health when we mean "mental illness." This is a useful, even necessary discussion, because what we say will shape public perceptions and public policy. Talk is never cheap!

Elaina Popovich, poet, who works with Lutheran School Services in Midland, Missouri, teaches us about the meaning of words.

YOU and I

by Elaina Popovich

I am a resident.
You reside.
I am admitted.
You move in.
I have behavior problems.
You are rude.
I am non-compliant.
You don't like being told what to do.
When I ask you out to dinner, it is an outing.
When you ask someone out, it is a date.
I don't know how many people have read the progress notes people write about me. I don't even know what is in there.
You didn't speak to your best friend for a month after she read your journal.
I make mistakes during my check writing program. Someday I might get a checking account.
You forget to record withdrawals from your account. The bank calls to remind you.
I celebrated my birthday yesterday with 5 other residents and 2 staff members. I hope my family sends me a card.
Your family threw you a surprise party.
I am on a special diet because I am 5 pounds over my ideal body weight.
Your doctor gave up telling you.
I am learning household skills.
You hate housework.
I am learning leisure skills.
Your shirt says you are a "couch potato."
My case manager and other professionals set goals for me for next year.
You haven't decided what you want out of life.
Someday I will be discharged...maybe.
You will move onward and upward.

GOOD NEWS from the STIGMA FRONT...THE SCHORR FAMILY AWARD

In 1975, when Si and Eleanor Schorr's 12 year old daughter was diagnosed with schizophrenia, her parents were told to "forget about her, that there was no hope and nothing available."

Today, thanks to medication, psychotherapy and her family's love and support, their daughter is leading an independent life. Wanting to do something they thought "would help the most," the Schorrs established the Fund to award work which might "destigmatize mental illness."

"The most important step that can be taken is the recognition of what this illness is all about. One of the of the things that impedes progress is that the public is still not aware of what serious mental illness is, how it's caused, how it affects families, and that it's treatable," Mr. Schorr says. (Psychiatric News, 9/15/95)

Briefly Noted...

Heavy Marijuana Use Associated with Residual Neuropsychological Effects in College Students....

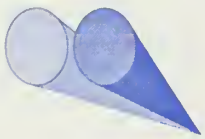
According to the February 21, 1996 issue of the Journal of the American Medical Association, a new study by researchers at McLean Hospital in Belmont, MA, reveals that college students who smoke marijuana regularly suffer from residual neuropsychological effects, such as attention impairment, even after a day of supervised abstinence.

The McLean research provides new and stronger evidence that cognitive abilities, such as taking an exam or remembering something that someone has just explained, are impaired more in heavy users than in light users.

The study was conducted by Harrison G. Pope, Jr., M.D.,chief of the Biological Psychiatry Lab at

McLean's Alcohol and Drug Abuse Research Center, and Deborah Yurgelun-Todd, Ph.D., director of neuropsychology for the Brain Imaging Center.

For more information, call Susan Craig, Public Affairs, McLean Hospital/ 617-855-2110 or Ann Madigan, DMH at 617-727-5500, ext. 242.



DMH Task Force on Trauma:

The mission statement of the Trauma Task Force is to transform the Massachusetts mental health system to be more responsive to the needs of DMH adults and child/adolescent priority clients who have experienced trauma. The Task Force will develop recommendations for policies and practices that will include awareness, sensitivity and skill in meeting the clinical and support needs of the survivors of trauma. The Task Force will directly assist in the development of education and training, of an information and referral system, of a research database, of clinical and programmatic standards and will serve as an ongoing resource for DMH needs in this area.

The following Committees are now established:

1) ***Expected Outcomes***
2) ***Dual Diagnosis***
3) ***Treatment and Rehabilitation***
4) ***Peer Support***
5) ***Child and Adolescent Services***
6) ***Practical Strategies and Training for Direct Care Staff***
7) ***DMH Research Database***

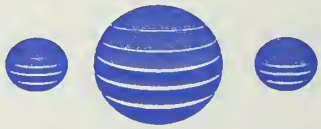
There is a need for family members to be part of these committees. Information can be obtained by contacting Connie Peters, Operations Director, at (617) 727-5500, extension 416.

A MEDICATION TASK FORCE,

chaired by Jean Crocker (Cape Cod CCSS Committee), has been formed to study all aspects of medication use, with special attention to new medications and their availability to those who could benefit from them. Besides Crocker, members of the task force include representatives from the public and private sectors, advocacy groups, the psychiatric and pharmaceutical communities and DMH Central Office.

Families, consumers and clinicians who have seen or known first-hand the success of clozaril therapy, say that this experience particularly commits them to the principle of the best and most appropriate treatment for everyone who suffers from mental illness.

The task force couldn't have been created at a better time. According to Psychiatric Times (December, 1995), the flow of "novel" and "atypical" psychopharmaceuticals "surged" through the pipeline in October, 1995. "The term atypical will be an anachronism soon," predicts David Daniel, M.D., director of the Washington Clinical Research Center. "Based on what's in the pipeline, these new compounds are likely to be 'typical' and main-stay in the not-so-distant future," he says.



THE HIPPOCRATIC OATH

is known to most of us as that admonition to physicians "to do no harm," but most of us are not aware that more than 60 treatises were attributed to Hippocrates. In his essay, "On the Sacred Disease," which is about epilepsy, Hippocrates writes, "It ought to be generally known that the source of our pleasure, merriment, laughter and amusement, as of our grief, pain, anxiety and tears, is none other than the brain. It is the organ which enables us to think, see and hear, and to distinguish the ugly and the beautiful, the bad and the good, pleasant and unpleasant...It is the brain too which is the seat of madness and delerium, of the fears and frights which assail us, often by night, but sometimes even by day: it is there where lies the cause of insomnia and sleep-walking, of thoughts that will not come, forgotten duties and eccentricities."

To say that mental illnesses are brain disorders is to be in good company.

"A good listener is not only popular everywhere, but after a while he knows something"
Wilson Mizner

GLOSSARY of MANAGED CARE

Group Model HMO: A type of HMO medical center where many different services are provided in unified medical center locations. Staff usually treat only HMO members.

Health Care Financing Administration (HCFA): The agency within the U.S. Department of Health and Human Services that oversees the Medicaid and Medicare programs. There are regional HCFA offices throughout the country, each responsible for working with a group of states.

Health Maintenance Organization (HMO): Prepaid or capitated insurance plans in which individuals and/or their employers pay a fixed monthly fee for services instead of a separate charge for each visit or service. The monthly fees remain the same regardless of the types or levels of services provided. Services are provided by physicians who are employed by, or under contract with, the HMO. HMOs vary in design. Depending on the type of HMO, services may be provided in a central facility or in a physician's own office.

Indemnity Health Plan: Also called fee-for-service. This is the type of plan that primarily existed before the rise of HMOs, IPAs, and PPOs. With indemnity plans, the individual pays a predetermined percentage of the cost of health care services usually up to an annual "stop loss" limit, and the insurance company (or self-insured employer) pays the other percentage. For example, an individual might pay 20 percent for services while the insurance company pays 80 percent. The fees for services are defined by the providers and vary from physician to physician. Indemnity health plans offer individuals the freedom to choose their healthcare professionals.

Independent Practice, Associations: IPAs are similar to HMOs, except that individuals receive care in a physician's own office rather than in an HMO facility, and participating physicians treat non-plan patients also.

Institution for Mental Disease (IMD): A facility of more than 16 beds in which at least 50 percent of the residents have a primary diagnosis of mental illness at time of admission. IMDs cannot receive Medicaid funds for services to persons ages 22-64.

Lead agency: In progressive mental health community support systems, a single agency is designated the lead agency and vested with full clinical and fiscal authority and responsibility for collaborating with clients in achieving their desired outcomes. Lead agency teams collaborate with clients to achieve outcomes by providing key services as well as accessing and contracting or otherwise arranging for services from external specialized agencies or other health and human services systems.

LOS: An acronym for length-of-stay, LOS is a term used to describe the number of days an individual stays in a hospital or inpatient facility.

Many of the terms used in this glossary are from A Glossary of Insurance Terms by "Mental Illness & Managed Care a Primer for Families and Consumers.

Join The CCSS Bulletin?

We hope you have enjoyed reading our Newsletter. We have a database (a sort of computerized telephone book) that allow us in a matter of seconds to retrieve people by specific areas of primary interest. If you aren't already on our mailing list or would like to be included we encourage you to fill this form and return it to us. Confidentiality is assured. We appreciate your interest, time, and enthusiasm.

Name_____
Address _____
City _____
State_____
ZIP_____
Telephone ( ) _____

Would you identify yourself (optional) as:

☐ Consumer ☐ Family ☐ Provider

Please list any specific interest in any of these area of mental illness:

1) ☐ Housing
2) ☐ Employment
3) ☐ Education/Return to School/Supported Education Programs
4) ☐ Substance Abuse
5) ☐ Medicaid, Medicare
6) ☐ Clubhouse
7) ☐ Advocacy on State Budget & Legislation
8) ☐ Parent of a child with serious emotional disturbances
9) ☐ SSI/SSDI
10) ☐ Welfare Reform

Interested in becoming involved in the CCSS planning?

BREAKDOWN OF NATURAL SERVICE AREAS/CCSSs & WHO TO CALL

WESTERN MASS.
James Duffy,
Area Director
413-584-1644
1 *Central/South Berkshire*
2 *Franklin/North Quabbin*
3 *Hampshire*
4 *Holyoke/Chicopee*
5 *North Berkshire*
6 *Springfield*
7 *Westfield*

NORTH EAST
Lorene Bourque,
Interim Area Director
508-851-7321
1 *Beverly*
2 *Greater Lawrence*
3 *Greater Lowell*
4 *Haverhill/Newburyport*
5 *Lynn*
6 *Wakefield*

METRO WEST
Theodore E. Kirousis,
Area Director
508-792-7400 2073
1 *East*
2 *West*

CENTRAL MASS.
Constance P. Doto,
Area Director
508-752-4681 Ext. 263
1 *Milford*
2 *Southbridge*
3 *Gardner*
4 *Fitchburg*
5 *Worcester*

METRO SOUTH
Barbara A. Leadholm,
Area Director 508-359-7312
ext.600
1 *Newton/South Norfolk*
2 *South Shore/Coastal*

SOUTHEAST
John P. Sullivan,
Area Director
508-580-0800 ext. 201
1 *Brockton*
2 *Cape Cod*
3 *Fall River*
4 *New Bedford*
5 *Plymouth*
6 *Taunton/Attleboro*

METRO-BOSTON
Clifford Robinson,
Area Director
617-727-4923 ext. 301
1 *Bay Cove*
2 *Cambridge/Somerville*
3 *Lindemann*
4 *Mass. Mental Health Center*
5 *Solomon Carter Fuller*

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The DMH Bulletin

Massachusetts Department of Mental Health Vol.1 No 5 SPRING 1996

Meet Commissioner Marylou Sudders

Since our last issue, Governor Weld appointed Marylou Sudders as Commissioner of the Department of Mental Health for the Commonwealth of Massachusetts. In this capacity, Sudders oversees a mental health care system that provides services to more than 80,000 residents, with an annual budget of $520 million.

The new Commissioner is not new to Massachusetts, nor to its Department of Mental Health. Her responsibilities here have included managing the closing of Metropolitan State Hospital while serving as its chief operating officer. She also was Area Director in Central Massachusetts and authored the first comprehensive policy manual for state mental health facilities. When not in state service, Sudders managed a federal homeless grant for the Massachusetts Association for Mental Health and served as administrator of Tri-City Mental Health Services in Malden. Before her appointment as DMH Commissioner, Sudders was Deputy Director and then Director of the Division of Mental Health and Developmental Services during her three years in New Hampshire. She holds a Master's Degree in Social Work from Boston University.

On March 7, 1996, Commissioner Sudders presented testimony to the House Ways and Means Committee on the DMH Fiscal Year 1997 budget. What she had to say to the legislators that day is a good indication of her philosophy, goals, priorities and commitments.

On Continuing Care Services: "Not every individual in an acute setting can be discharged directly to the community; some need extended hospital care."

On the DMH/DMA Initiative: "This partnership allows DMH to invest $9 million currently spent on acute care inpatient programs to further expand continuing care services. This reinvestment will provide expanded housing, case management, dual diagnosis treatment, clubhouse programs and medication monitoring. These dollars also will help the Department to address historical inequitable resource distribution."

On Collaborative Assessment Program/Services for Children (C.A.P.): C.A.P. is an interagency DMH and DSS pilot project in the Southeast Area. The major objectives are to conduct prompt assessments for children with serious emotional disturbance; better coordinate their care; prevent expensive out-of-home placements. The program is achieving its goals and is worthy of expansion. The Governor's budget submission expands the program statewide and recommends $585,000 for DMH and $1.9M for DSS. The Commissioner urges that the legislators support this initiative.

The Commissioner also addressed issues dealing with homeless services, forensic mental health issues, outpatient services, salary increases for direct care workers and the development of a software system that will serve as a model for all health and human services agencies in gathering demographic information.

While acknowledging the budgetary challenges facing the Department, Sudders reminded the members of the committee that "there are no quick fixes."❑

Inside This Issue:

OUTPATIENT COMMITMENT..Is it effective and humane or is it a violation of civil liberties?

By Ann Madigan

Keep in mind that nationally:

- ***15,000 people with mood disorders commit suicide every year;***
- ***3,000 people with schizophrenia kill themselves every year;***
- ***Each year, more than 30,000 individuals with serious neurobiological disorders are in jail;***
- ***More than 100,000 people with mental illness live on the streets or in shelters.***

While a variety of reasons account for these factors, and there are many ways to address them, one has resulted in a move toward changing involuntary treatment laws. Outpatient commitment requires a person who is "gravely disabled" by mental illness to comply with a treatment program. Non-compliance may result in a person's hospitalization and sometimes forced medication.

Knowledgeable, caring people have taken widely divergent stands on this emotionally charged issue.

PRO: E. Fuller Torrey, M.D., a psychiatrist and researcher with the National Institute of Mental Health testifying before a Senate Committee, said, "Involuntary commitment has shown to be highly effective in keeping individuals with serious mental illnesses on medication and out of hospitals." He pointed out that the studies in two states with outpatient commitment statutes, North Carolina and Arizona, reported decreased hospital admissions, shortened stays and significantly increased outpatient visits and medication compliance.

CON: At the same hearing, a lawyer, a former patient and a psychiatrist all argued that the proposal would infringe upon consumers' civil liberties. Howard Goldman, M.D., Ph.D., testifying on behalf of the Bazelon Center for Mental Health Law in Washington, D.C., called the proposal a drastic and counterproductive step. "It deprives the individual of his or her liberty and often disrupts a clinical relationship, creating an unenforceable barrier to treatment recommendations." Also arguing against the move were the National Association of State Health Program Directors, the National Mental Health Association and the consumer council of the National Alliance for the Mentally Ill.

A proposal offered by Sen. Nancy Kassebaum,(R.-Kan.), would have taken ACCESS funding and used it as incentive grants for states to develop outpatient commitment programs, but she withdrew it from the reauthorization bill for Substance Abuse and Mental Health Services (SAMHSA).

In trying to sort out whether forcing people to accept treatment helps the seriously mentally ill, outpatient commitment is about to get its first rigorous test in New York and North Carolina. The New York study is being carried out as part of a three-year pilot program mandated by state law, before New York decides to sanction further use.

The set-up in both states will be similar, with half of the patients randomly selected willingingly receiving services and the other half treated under commitment order. All of the patients must meet criteria for discharge. Each will have an individualized treatment plan with opportunities for psychotherapy, psychopharmacology, housing assistance, case management and day treatment.

This will certainly continue to be a controversial issue for consumers, families of the mentally ill and mental health professionals. They must ponder the question, is "involuntary treatment" an oxymoron.❑

(Ann Madigan is the DMH Anti-stigma Coordinator. Please note that this article does not reflect the views of the Department of Mental Health.)

A sure way for one to lift himself up is by helping to lift somone else.
Booker T. Washington

Finishing Some Unfinished Business.....

By Marylou Sudders

It is a pleasure and an honor to be back at the Department for a third "at bat."

Three months on the job hardly tells me every thing I need to know about what we are doing and how we are doing it. But permit me to offer some impressions and observations based on crisscrossing the state, talking to consumers, family members, public employees, provider staff, citizens who devote countless hours of time on Boards of Trustees, Area and Site Boards, legislators, AMI chapters and other key stakeholders in the public mental health sector. We have had open and frank discussions of issues, concerns and opportunities.

The Department appears to have been on fast forward to a destination that remains somewhat unclear. I am not certain whether there is consensus among the many stakeholders or even the majority of them when it comes to Department goals and objectives.

There are some wonderful examples of strong working relationships and collaboration across the state. There is a genuine interest among many participants to communicate, to share ideas, and to solve problems together. But this is not true state wide. Gems of innovative initiatives are evident in corners of the state, but there is little cross fertilization across the Commonwealth.

There is some collaboration among a few statewide mental health organizations, gener ally around a particular topic like the budget. However, it is not broad based.

Within the Department, there are some ter rific ideas in Areas that have not been sup ported, nurtured or communicated state wide. There are numerous examples of service initiatives and infrastructure improvements that would strengthen the overall service delivery system, but they are not universally applied.

> ...."it is my impression that there has not been a strong mental health agenda in Massachusetts. It is time to establish one because there is much at stake and the consequences of not doing so will be unacceptable."

The DMH budget has been relatively flat for several years, yet the need for services has not diminished. I recently met with about 50 individuals living at the Fenwood Inn at the Massachusetts Mental Health Center in Boston. In response to a question, about a third of the group indicated that they were waiting for openings in residential programs. And, as we know, more than 200 people in state hospitals are waiting for community services and placement at any point in time. There are a myriad of other examples.

Simply put, it is my impression that there has not been a strong mental health agenda in Massa chusetts. It is time to establish one because there is much at stake and the consequences of not doing so will be unacceptable.

Yet, we do not speak with one voice. Rather than channel our energies into a shared vision, we have allowed the diversity of perspectives and opinion to divide us. I believe we need to take our individual voices and come together to shape a common agenda for the future.

For the past three years, I have had the pleasure of working in New Hampshire. That experience renewed my faith and re-energized my commitment to public service. I have returned with three lessons learned:

1. ***Public mental health authorities must provide the commitment to meet the needs of individuals with co-occurring mental illness and substance abuse disorders. The facts are staggering. If you have schizophrenia, the odds of abusing substances are four-and-a-half times greater than the general population experiences. Our collective wisdom and personal experiences tell us that people with mental illness and a substance abuse diagnosis experience greater poverty, higher rates of hospital readmission, more treatment failure, more homelessness, higher rates of physical illness and greater incarceration in jails and prisons. Concurrent treatment strategies must be employed in a unified system that shuns the days of saying it is some other agency's responsibility.***

2. ***Research and linkage among academic institutions and the public sector only strengthens our support and service system. Training programs that provide real opportunity for professional growth and development in addition to a public service career track are essential to the quality of our service system.***

3. ***There can and must be a strong mental health voice among key stakeholders who agree on an agenda for success. Differences must be set aside; the focus placed on areas where all mental health constituents agree.***
   In New Hampshire, one visible result was insurance parity legislation that passed.

Our basic underlying principles are not complicated. The array of acute and continuing care services must act as a safety net for the state's most vulnerable citizens; quality cannot be compromised for cost savings; movement must be created within the system to ensure services are clinically appropriate and cost effective; a balance of community and hospital services is essential.

Together we can address the issue of stigma and discrimination endured by people with mental illness. And, together we can face the challenges presented by a changing health care environment with certainty. I look forward to the opportunity to work with you.❑

Insincerity is the enemy of clarity. ***George Orwell***

The DMH *Bulletin*

A quaterly Publication of the Massachusetts Department of Mental Health, reporting state news and relevant information for consumers and their families, mental health professionals, vendors of services, and all citizens interested in the goals and mission of this Human Service Agency

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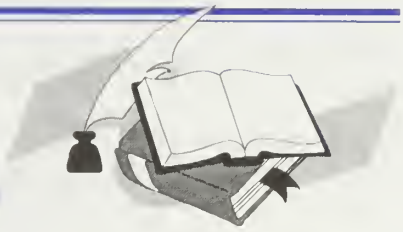
CONFERENCES and FORUMS...

Learning Opportunities..



The Massachusetts Alliance for the Mentally Ill 1996 Convention was held on May 11 at the Holiday Inn in Taunton, MA. The speakers included Marylou Sudders, Commissioner of the Department of Mental Health, Peter Smith, President of the Massachusetts Alliance, Rona Purdy, President of the National Alliance, Jill Bolte Taylor, Ph.D. and Laurie Schiller, author of the book, *The Quiet Room*.

Smith's was a farewell address, since he is stepping down from the presidency. The Commissioner's remarks drew enthusiastic applause, especially when she stated her support of parity of insurance for brain disorders and when she promised that "quality would not be compromised by cost." Dr. Taylor made a plea for for brain donations, (call 1-800-BRAIN BANK), and elicited laughs when she assured her listeners, "I'm in no hurry." Rona Purdy, always an energizing presence, called on the members to become active in the Alliance's Anti-discrimination Campaign and to begin by passing the by-laws which would make Massachusetts a chartered member of NAMI. Later, at their business meeting, they did just that.

It was Lori Schiller and her story of recovery and hope that most stirred those in attendance. Watching the video of Schiller's interview with Dianne Sawyer on Prime Time which won an Emmy and hearing her own harrowing account of the years she spent battling the voices of schizophrenia, brought the audience to their feet in honor of her courage.

Several awards were presented:

The First Annual Rothstein Award to David Osser, M.D., Assistant Professor of Psychiatry at Harvard Medical School and Tufts Medical School, chairman of the Task Force on Psychopharmacology for the Massachusetts Psychiatric Society, psychopharmacology consultant at several area hospitals and is staff psychiatrist at Brockton/West Roxbury VA and Taunton State Hospital, "whose compassion and dedication advances clinical psychiatry and the treatment and care of persons with serious mental illness."

AMI of Massachusetts Public Service Award to Joseph DeNucci, State Auditor since 1987, for "his particular sensitivity and concern for issues that affect persons with psychiatric disabilities and their family members."

AMI of Massachusetts DMH Employee of the Year to John F. Sullivan, Ph.D. for "helping to foster a spirit of collaboration by working closely with and being responsive to family members."

AMI of Massachusetts Media Award to Lizbeth Kowalczk, education reporter for the Patriot Ledger, for "her insightful and comprehensive reporting on mental illness."❑

Internal Audit Team to Check Contracts

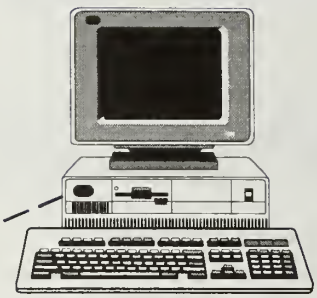
by Perry Trilling & Patricia Mackin

The DMH Central Office Contracts Unit is refining its responsibilities so that procurement laws and regulations are followed across the state. As part of this new focus, Central Office staff is training field personnel who work on contracts concerning policies and procedures that reinforce state purchasing laws, promote effective monitoring of services and payment systems.

A significant new responsibility of the Contracts Unit involves the creation of an internal audit team. It will conduct audits at least once a year on a random number of contracts within each Area to ensure policy and regulatory requirements are met. The audits will examine activities at each step of the contracting process; starting with Request for Proposals (RFP) development through the awarding of the contract. This will include contract monitoring, recordkeeping and vendor payments. Through these audits, deficiencies in an Area's contracting processes will be identified and remedied while the audit results are used in statewide training and policy enhancements.❑

(Perry Trilling is the Assistant Commissioner for Administration and Finance - Patricia Mackin is the Director of Contract Administration, Audit and Systems)

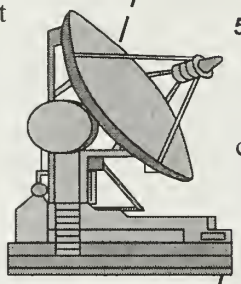
Applied Information Technology (AIT) ...an Update..



By Larry Hookey

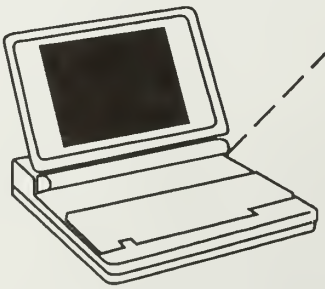
The Department is developing new technology that will allow us to monitor and manage the flow of resources to consumers more effectively.

The Registration and Enrollment System (R.E.S.), will provide for the first time a single point of entry for all service-related data throughout the Department. R.E.S. will collect information about people who use, or seek to use, DMH services. Once collected, the sys- tem will provide accurate, timely and secure access to a person's current and past involvement with the DMH service system. This information will be available, on-line across the state and around the clock, to help individuals to make more informed decisions.



The system will be consumer focused and answer the following four fundamental, recurring questions:

1) **Who uses DMH services?**
2) **What is their financial eligibility?**
3) **What services do they use?**
4) **What services do they need?**



The data and functions currently captured in some automated DMH systems will be consolidated into R.E.S.. This ensures data integrity and eliminates duplication of statistical information and effort. Other existing automated systems will interface to R.E.S. to form a seamless, integrated system.

A prototype of the system is being completed with demonstrations planned in all areas over the next few weeks. Test site installation of R.E.S. is planned for the early fall with an early 1997 target for the first field site.

R.E.S. will be complemented by the Consumer Accounting and Billing System (C.A.B.S.) which is designed to:

1) ***Provide a comprehensive consumer accounting and billing system;***
2) ***Consolidate and replace the existing multiple billing systems currently in use across the Department;***
3) ***Collect revenues in a timely fashion;***
4) ***Track service utilization extensively;***
5) ***Improve management of accounts receivable.***

The implementation target is mid-1997.

The R.E.S. and C.A.B.S. project teams are comprised of Advanced Information Technology (AIT) staff and staff from the business unit. Each has a Project Manager from AIT and from the business area. The project teams have representations from 2 areas and Central Office.

These systems will replace the Department's incomplete and outdated production systems. They will serve as the single source for all of the Department's program-related information needs. Facilities will be obligated in the future to supply data to R.E.S. as specified by the Department, assuring timely information to assess their performance.

R.E.S. and C.A.B.S. represent two thirds of the planned new technology system. The third strategic section is the development of a Clinical Information System.

In addition to the system development, DMH has implemented a management information system, DMH Warehouse. It is an application utilizing current technology to link client information from a variety of legacy systems. The information is available statewide, with appropriate security, on the DMH Network. The Warehouse utilizes tools allowing structured questions to be answered. Monthly Management Indicators are included in the Warehouse, providing on-line access to graphs and detailed information previously unavailable or published on paper with limited information.❑

(Larry Hookey, Assistant Commissioner for the Applied Information Technology.)

KIDS' page....

by Marion Freedman-Gurspan

Governor Weld proclaimed May 5-11 Children's Emotional and Behavioral Disorders Awareness Week in Massachusetts. Praise is due to Marian Butler, Nancy Collier and Lisa Lambert, three parent coordinators, who organized this initiative and enlisted the tactical and financial support of the Department of Mental Health, the Parent Professional Advocacy League, professional organizations and corporate and individual donors.

May 5-11
Children's Mental Health Week

The aims of this initiative, popularly known as Children's Mental Health Week, were to raise public awareness of the growing number of children with emotional and behavioral disorders, and to decrease the stigma associated with these disorders. Studies show that at any given time, at least one out of five young people experiences a behavioral, emotional or mental health problem, and five percent of all children and adolescents have disorders that severely disrupt their daily functioning. Of high school students in Massachusetts, 20% have said they had a plan to commit suicide, and 10% acknowledged attempting suicide in the past year. The majority of the public lacks even a basic understanding of these disorders, the needs of these children, and the emotional, social and financial impact on families.

Children's Mental Health Week was publicized in many ways. T-shirts, buttons and turquoise ribbons advertising Children's Mental Health week were distributed. A Night at the Wang, II, an evening of multi-cultural song and dance presented by children and adolescents of DMH contracted residential programs in the Northeast Area, was the opening event. On May 1, a Today Show host interviewed Marian Butler who was carrying a large Massachusetts Children's Mental Health Week sign outside the studio in New York City.

During the week, the director of the Central Middlesex Mental Health Association interviewed Lambert and Butler for Acton cable television. The MetroWest Area sponsored a camp fair where summer camps catering to children with emotional and behavior problems were displayed. The Mass. School Psychologists Association distributed information packets to all of its members, and encouraged information sessions in its schools. In Chelmsford, all students wore turquoise ribbons during the week. Press packets were distributed to media outlets across the state, and several papers, including the Cape Cod Times, and the Northwest Journal published editorials. ❑

A Night at the Wang II.... a chance for kids to show their superior talents !!!

Over 300 attendees, including proud parents, were treated to a spectacular performance of multicultural music, song and dance by students from the Department of Mental Health (DMH) contracted residential programs in the Northeast Area on April 30, at the Wang Center for the Performing Arts in Boston. A Night at the Wang II involved 75 emotionally disturbed children and adolescents and a team of professional performing artists and educators known as Express Yourself. The student performers range in age from 6 to 19 years of age and are students at Crossroads in Bradford, Cornerstones in Beverly, Highfields in Lawrence, Foundations in Topsfield, Solstice in Rowley, Diversion House in Danvers and the Charles River Program in Taunton. Other featured guest artists included Stan Strickland and Ascension and the Medicine Band.

This project was made possible through funding from the Consumer-Run initiative small grant funds, administered annually out of DMH central office. Consumer-Run Initiatives are a new and evolving reality. A primary reason for forming this project was the limitation of the service system, and the stigma attached to kids with mental illness about their not being capable to be productive human being.
Consumer-run funding are intended to provide the opportunity for people who have used the mental health system to have their own organization. The common objective of all those involved in these projects is to improve the quality of life for themselves and other consumers.

The magnificent theater foyer was donated for the evening by Josiah A. Spaulding, Jr., President and Chief Executive Officer of the Wang Center, through YOUNG AT ARTS, the Wang Center's educational outreach initiative. The lively performance occured amongst a colorful landscape of urban setting sculpture and other artwork created by the students. The artwork will be exhibited in July at the Ashwell Gallery in Beverly.

Express Yourself artists share a common philosophy, encouraging students to be in touch with their own sense of creativity and providing opportunities to build individual self-esteem. "We have been working to bring integrated arts to students in a variety of settings for several years," said Paula Belezos Conrad, founder and co-director of Express Yourself. "This project allows children a natural, creative outlet for healthy self-expression. This is very important for mentally ill kids who feel tremendously isolated from the mainstream."

"This is a wonderful opportunity for children and families to share this very exciting experience", said Marylou Sudders, DMH Commissioner. "Children and families who experience mental illness have lost these types of opportunities to establish positive milestones and participate in healthy, creative expression." ❑

(Marion Freedman-Gurspan is Director of Special Projects, Division of Child and Adolescent Services.)

Change in Law Won't Solve Pain of Patients Isolated by Stigma and Prejudice...

...the Wall Street Journal reported on March 19, 1996. Although, according to the Journal, things are changing now, society has wounded the dignity of these patients and their families.

Most painful of all for the patients is the fact that many of their families want nothing to do with them. One of the patients, Osamu Usami, has only two living relatives who have all but disowned him and, as far as he knows, have never told their children or grandchildren about him. Around the world, people like Usami have endured brutal discrimination for millenia. Going back to biblical times, people suffering from diseases, untreatable then, were reviled as outcasts. Effective drug treatments have been available for decades, yet some disabled patients who have nowhere to go remain in state hospitals.

The Journal points out that keeping the disease hidden has helped perpetuate the stigma.

Is this article about mental illness? It could be, but actually, it describes the situation in contemporary Japan and the illness is leprosy.❑

The Medium is the Message:

The Department has sponsored two video projects that will be used to educate people about the realities of mental illness and raise awareness of the subtle and not so subtle stigmatizing messages that pervade our society.

The first video targets medical students, who, like the rest of us, base many of their beliefs on what they read in newspaper and see on television. Harvard medical students who do their psychiatric rotation at the Massachusetts Mental Health Center hear Dr. Ken Duckworth's stigma lecture on their first day of Grand Rounds. Complete with examples from children's movies, Dr. Duckworth illustates how people with mental illness and their treaters are portrayed as violent, as evil, as con-men. "With these messages, we are raising a whole new generation of 'Not in My Backyard' adults," says Dr. Duckworth.

The video captures the essence of Dr. Duckworth's presentation and will be available to medical schools with a curriculum guide. At recent meeting of the American Psychiatric Association (APA) in New York City, Dr. Duckworth shared his enthusiasm for the need for this instruction at their own schools.

The second video was produced in response to a DMH request for a proposal "to create a pilot program that would broadcast on radio or television and would address the concerns and issues of people with mental illness, seeking the participation of consumers at every level of planning and production." The grant was awarded to Foundations, Inc. of Holyoke, MA., which produced a half hour television show called, The Road to Hope: Psychiatric Survivors Challenge the Stigma of Mental Illness. It aired on WGGB/ABC, Channel 40 in Springfield on March 20, 1996 at 7:30 PM. It will show again on June 4, 1:35 AM, June 8, noon, and June 23, 1:30 PM. ❑

For more information, call Foundations at (413) 536-8588.

Briefly Noted...

Clozapine Linked to Reduced Smoking; Drug May Curb Nicotine Craving

A study published in the Journal of Clinical Psychiatry shows that clozapine leads to a reduction in smoking among patients with schizophrenia. The prevalence of smoking in this group of patients runs as high as 90 percent.

Several factors may account for these higher rates of smoking, including alleviation of depressive, psychotic and anxiety symptoms through the effects of nicotine on relevant neurotransmitter systems. Smoking also may relieve some of the side effects of psychotropic medications.

Tony George, M.D., a coinvestigator at the Yale University Connecticut Mental Health Center in New Haven, reports studying 29 outpatients enrolled in the clozapine clinc of a community mental health center. The most significant decrease was associated with the heavier smokers. There also are anecdotal reports linking clozapine to reduced alcohol and opiate craving.

....More on Smoking:

At St. Margaret's Hospital in Dorchester, the Center for Community Responsive Care (CCRC) initiated a smoking cessation program tailored to the unique situation and needs of people who are mentally ill and homeless.

Since the passing of the statewide cigarette tax in 1993, Massachusetts has initiated a systematic effort to reduce the number of residents who use tobacco and support programs that prevent young people from starting to smoke. Despite the high incidence of smoking among the homeless mentally ill, help for this population has been nearly nonexistent.

In the winter of 1995 (and what a winter!), CCRC met this challenge with weekly sessions that included a support/buddy system, exercise, meditation and stress reduction techniques, instruction and discussion of nicotine and medication interaction, as well as consumer leadership development skills.

Even when transportation plans faltered and the temperatures plummeted, the participants arrived to attend these meetings

For more information, call Gretchen Kinder at (617) 265-4400.

Linguistic Ability in Early Life and Alzheimer's Disease in Late Life: Findings from the Nun Study

A fascinating study of a population of nuns over six decades suggests that low linguistic ability is a strong prediction of Alzheimer's. The participants, members of the Sisters of Notre Dame, who have had very similar occupational, dietary and environmental experiences over their adult lives, also agreed to donate their brains to the study. Findings from the neuropathology of the 25 sisters who have died, indicate that individuals with greater linguistic ability when young are more resistant to the cognitive effects of Alzheimer's disease. Alternatively, the study could indicate that Alzheimer's may begin early in life and only becomes manifest after decades of deterioration of neural function.

My love for an institution is in direct proportion to my desire to reform it.

John Stewart Mill

It's All in the perspective

Who do YOU see?
The young woman
or
the old one?

WANTED

A new name for the DMH Bulletin, one which will be meaningful and memorable and will reflect the mission and goals of the Department. This new publication seeks to interest people inside and outside of the agency and is replacing the CCSS Bulletin. Not only will the name be different, but the content will be more wide-ranging. It will include news from across the state and information from the fields of psychiatry, children's services, budgeting and whatever current data will be useful to its readers.

This change does not affect the concepts embodied in the Comprehensive Community Support Systems. In a memo to staff regarding the name of the Bulletin, Marylou Sudders said: "The local area and site boards retain their advisory roles, planning continues, and community service systems deliver what clients want and need to help them live as independently as clinically appropriate."

Clear language promotes careful thinking and leads to better understanding.

Please meet this challenge with us and submit your suggestion to the editors. Thanks

Name_____
Address _____
City _____
State_____
ZIP_____
Telephone ( ) _____
Would you identify yourself (optional) as:
☐ Consumer ☐ Family ☐ Provider

Please list any specific interest in any of these area of mental illness:
1) ☐ Housing
2) ☐ Employment
3) ☐ Education/Return to School/Supported Education Programs
4) ☐ Substance Abuse

Join The DMH Bulletin?

We hope you have enjoyed reading our newsletter. We have a database (a sort of computerized telephone book) that allows us in a matter of seconds to retrieve people by specific areas of primary interest. If you aren't already on our mailing list or would like to be included we encourage you to fill this form and return it to us. Confidentiality is assured. We appreciate your interest, time, and enthusiasm.

5) ☐ Medicaid, Medicare
6) ☐ Clubhouse
7) ☐ Advocacy on State Budget & Legislation
8) ☐ Parent of a child with serious emotional disturbances
9) ☐ SSI/SSDI
10) ☐ Welfare Reform

Interested in becoming involved in the local service system planning?

BREAKDOWN OF NATURAL SERVICE AREAS & WHOM TO CALL

WESTERN MASS.
James Duffy,
Area Director
413-584-1644
1 Central/South Berkshire
2 Franklin/North Quabbin
3 Hampshire
4 Holyoke/Chicopee
5 North Berkshire
6 Springfield
7 Westfield

NORTHEAST
Lorene Bourque,
Area Director
508-851-7321
1 Beverly
2 Greater Lawrence
3 Greater Lowell
4 Haverhill/Newburyport
5 Lynn
6 Wakefield

METRO WEST
Theodore E. Kirousis,
Area Director
508-792-7400 ext. 2073
1 East
2 West

CENTRAL MASS.
Constance P. Doto,
Area Director
508-752-4681 ext. 263
1 Milford
2 Southbridge
3 Gardner
4 Fitchburg
5 Worcester

METRO SOUTH
Barbara A. Leadholm,
Area Director
508-359-7312 ext.600
1 Newton/South Norfolk
2 South Shore/Coastal

SOUTHEAST
John P. Sullivan,
Area Director
508-580-0800 ext. 201
1 Brockton
2 Cape Cod
3 Fall River
4 New Bedford
5 Plymouth
6 Taunton/Attleboro

METRO-BOSTON
Clifford Robinson,
Area Director
617-727-4923 ext. 301
1 Bay Cove
2 Cambridge/Somerville
3 Lindemann
4 Mass. Mental Health Center
5 Solomon Carter Fuller

The DMH *Bulletin*
25 Staniford St.
Boston Ma. 02114

Please Recycle This Newsletter

Address Correction Requested

The DMH Bulletin

Massachusetts Department of Mental Health Vol.1 No 6 SUMMER 1996

Message from Commissioner Marylou Sudders

Our $523.7M budget for FY'97 allows us to take another step in the continued restructuring of the public mental health system in the Commonwealth. More importantly, we can place increased emphasis on flexible supports, helping people move through a continuum of care towards recovery.

Legislators agreed to the transfer of about $9M in savings from the Division of Medical Assistance/ Department of Mental Health initiative for expanded DMH continuing care and community-based services that will ensure the movement of more clients through the system. Area Directors, working with Area and Site Advisory Boards, have submitted proposals detailing how they plan to use their allocations. The Area resources are apportioned based on prevalence of mental illness and funding equity. This will help the Department to address inequitable, historic resource distribution in the lowest funded geographical parts of the DMH service system.

The budget does contain legislative language specifically earmarking $4.3M from the DMA/DMH savings to the Northeast Area, the lowest funded segment in our service system. It is the total we had specified in discussions with House and Senate Ways & Means staffs during budget deliberations.

We have transferred about $30M to DMA to provide emergency and acute mental health services for 30,000 non-Medicaid DMH clients. DMA has contracted with the Massachusetts Behavioral Health Partnership to administer the Division's $200M expanded mental health and substance abuse plan.

Although the budget earmarked only $2.5M to cover an historic $5.5M Metro Boston deficit, the remaining $3M was approved in the year-end supplemental budget. We have filed a report with the House and Senate Ways & Means Committees detailing the causes of funding deficiencies in Metro Boston. It also outlined what we accomplished in restructuring the service delivery system.

Although statewide expansion of the Collaborative Assessment Program (CAP), a Department of Mental Health/Department of Social Services pilot project in the Southeast Area, was not funded, we have high hopes that it will be in the future. And with good reason. An independent evaluator matched a sample of children who utilized the CAP program over the first six months with a sample from the first six months of the previous year. Of the 1994 group who did not have the benefit of CAP assessments and services, 80% ended up in residential care. Of the 1995 group utilizing CAP, only 20% ended up in residential care. The Southeastern pilot, which will be

Continued to next Page

Inside This Issue:

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funded again by DMH and DSS in FY'97, was launched in July 1995. It provides better, more coordinated assessments and services to children and adolescents and diverts care from high cost residential placements.

I am glad to note that the Annie E. Casey initiative, a project to restructure the financing and delivery of children's and family mental health services in the Lower Roxbury, Mission Hill, and Highland/ Washington Park neighborhoods in Boston, retained its funding of $3M.

A four percent salary increase for direct care workers employed by providers contracting with DMH and other health and human services agencies was approved by the legislature. Of the $14M appropriation, $2.8M will go to direct care workers of providers contracting with DMH. This is a small, but significant step towards stabilizing the high turnover rate of direct care workers because of low salaries.

Forensic mental health intervention services at Barnstable and Middlesex Houses of Correction will be expanded in light of $282,000 in additional funding in the budget. Interagency service agreements are being worked out with the county sheriffs. Quality of care oversight will be maintained by DMH.

Although the budget falls $6.8M short of DMH's original request and $2.1M less than the House I version submitted by the administration, it moves overall allocations up from the $518.9M we had to work with a year ago. It calls for $53.5M in revenue, but I believe we can reach this elevated goal.

Overall, individual legislators and their staffs listened when we presented our case and I am pleased with the way our budget concerns were received. Renewing legislative acquaintances has convinced me that we need to strengthen our ties and work with the leadership and their staffs on a year-round basis. We have begun the process by educating and explaining the critical components of a strong public mental health system that include flexible community-based programs, cost efficient state hospitals and high quality purchased acute inpatient and diversionary services. This will go a long way in allowing us to serve people with mental illness with more appropriate, cost effective services in the future.

Marylou Sudders

Commissioner

The DMH *Bulletin*

A quaterly Publication of the Massachusetts Department of Mental Health, reporting state news and relevant information for consumers and their families, mental health professionals, vendors of services, and all citizens interested in the goals and mission of this Human Service Agency

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amadigan@state.ma.us

The DMH Mission

As we know, the public mental health delivery system continues to adapt in a rapidly changing health care environment. DMA has been creating a system that emphasizes flexible supports, helping people to move through a continuum of care toward a life that is as self sufficient as clinically appropriate.

As part of the process, it is essential to step back, look again at the Department's mission and principles, and to establish goals and objectives that can be reasonably attained in this new fiscal year.

The Mission

The mission of the Department of Mental Health is to improve the quality of life for adults with serious and persistent mental illness and children with serious mental illness or severe emotional disturbance. This is accomplished by ensuring access to an integrated network of effective and efficient services that promotes consumer rights, responsibilities, rehabilitation, and recovery.

DMH is committed to the following principles:

1. Providing responsive, high quality, cost effective services.
2. Focusing support on the most vulnerable citizens in the Commonwealth.
3. Designing programs using current scientific research, evaluation studies and program outcome data.
4. Promoting opportunities for individuals with mental illness to participate in rehabilitation and recovery regardless of how severe their symptoms or pervasive their disabilities.
5. Offering consumers appropriate choices among services that are tailored to meet individual needs.
6. Valuing managers who are able to engage their colleagues and staff in entrepreneurial, innovative leadership that will improve the system.
7. Valuing input from a wide public audience and recognizing that community advocacy and advisory groups are an essential component of system planning.
8. Eliminating barriers to services wherever they exist.
9. Exploring and applying new technologies to ensure quality, cost effectiveness and the efficient use of public resources.
10. Assuring that the cultural and ethnic diversity of clients and staff are respected in the design and delivery of services.

Goals and Objectives

Goal No.1

Direct the Department of Mental Health in a manner that instills the public's confidence.

Objectives:

Establish a Senior Management Team that includes experience in field operations, managed care and the state system;

2. Develop understanding and support across the Department of a strategic DMH agenda;
3. Keep the legislature informed of DMH's strategic initiatives and priorities;
4. Strengthen the linkage with constituency groups, including providers, advocates, and other interested parties;
5. Assess the public's interest, awareness and priorities for public mental health services.

Goal No.2

Manage Department Of Mental Health resources to ensure positive clinical outcomes and cost-effectiveness.

Continued to Next Page

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Objectives:

1. Implement a standardized statewide Registration and Enrollment System (RES);
2. Implement a statewide eligibility assessment program for continuing care clients;
3. Implement the DMA / DMH Interagency Service Agreement (ISA);
4. Develop the data elements needed to describe, plan, and measure a balanced managed care service system;
5. Ensure the appropriate use of all DMH facilities;

Goal #3

Reframe the DMH regulatory authority in the new health care environment.

Objectives:

1. Review DMH regulations to reduce the unnecessary regulatory burden and comply with Executive Order 384, creating a December 31, 1996, "sunset" for all current regulations.
2. Propose a new regulatory structure that is consistent with the DMH mission.
3. Provide a statewide opportunity for input from staff, citizens, consumers, family members, mental health professionals, and other interested parties in creating the new regulatory structure.
4. Carry out a statewide communication and education process to promulgate the new regulations and inform members of the public mental health community.

Goal No.4

Promote consumer rights, responsibilities, and recovery opportunities.

Objectives:

1. Establish consistent consumer rights and responsibilities and assure their understanding across the state;
3 Promote consumer involvement throughout the Department;
4. Combat the stigma of mental illness.❑

E-Mail to the Editor:

Praise for the DMH Bullettin comes from D.J. Jaffe of the National Alliance for the Mentally Ill, with this suggestion concerning the smoking cessation program for the mentally ill homeless people conducted at St. Margaret's Hospital; "My advice is first get them housing, then work on smoking. Next we will have finishing schools for people who have been kicked out of state hospitals."

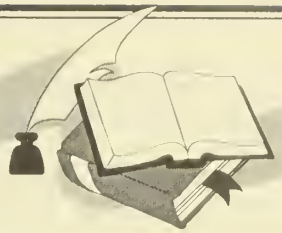
Reply from the Editor:

This program is aimed at helping people who find ubiquitous smoking strictures almost intolerable. Shelters, clinics, day programs, halfway houses, even the subway, are all hurdles for the incessant smoker.

There is a long and consistent history of scientific literature suggesting that individuals with mental illness die younger than people in the overall population. Poor health habits, including a high incidence of smoking, are among the causes. Too little attention has been paid in the past to the medical needs of people with psychiatric disorders. The program at St. Margaret's is addressing this issue.

CONFERENCES and FORUMS...

Learning Opportunities..



Breaking Barriers, Building Bridges: Understanding the Needs and Preferences of Trauma Survivors, May 23, 1996, Framingham State College...provided an opportunity for direct care staff, mental health professionals and consumers to meet and discuss the issues of "Impact of Restraint and Seclusion," "Staff/Survivor Communication," "Making Sense of Self-injury," and "Expressions of Trauma in Adults, Children and Adolescents." For more information about this conference call Pam Mason at the Office for Consumer and Ex-Patient Relations (OCER) at 1-800-221-0053 or 617-727-5500 x 405.

Clubhouses and Housing: A Partnership that Works, June 13, 1996, Worcester...with opening remarks from Carolyn Schlaepfer, Deputy Commissioner, DMH, Bernard Carey, Jr., Executive Director, Massachusetts Association for Mental Health, and Michael McAuliffe, Clubhouse Coalition. Commissioner Marylou Sudders was the guest speaker at lunch. Clubhouse programs are a significant part of the Department's network of community-based services that provide the opportunity, for adult with mental illness, to be part of a community offering social, vocational, educational and residential services and support. Workshops covered such topics as "How to Find Funding," "Tenant Rights and Responsibilities," "How to Start a Housing Search," and "Housing on a Shoestring." The presentation, "Innovative Clubhouse Housing Programs and a Vision of the Future," took a look at some exciting new programs and pointed out where clubhouses can and should go in the future. For more information, call Joanne McKenna at (617) 727-5500 x 370.

The National Alliance for the Mentally Ill (NAMI), Nashville, Tennessee,July 5-9, 1996.... this year, along with its usual emphasis on advocacy and research, NAMI focused on the NAMI Campaign to End Discrimination. Rona Purdy, outgoing President, called it "the last, large social movement of this century." She exhorted her listeners to seize the opportunity to get insurance coverage for brain disorders, telling her audience, that "if we can't change minds, we can change policy." She predicted, "We're going to change the world. This is our issue, this is our time."❑

SAVE THE DATE

Affective Disorders: State of the Art Review The annual teaching conference sponsored by the Massachusetts Department of Mental Health, Harvard Medical School and the University of Massachusetts Medical Center is scheduled for Thursday and Friday, September 19-20, 1996 at the John F. Kennedy Library, Columbia Point, Boston, MA. For more onformation call Judy Pina at (617) 727-5500 x 417.

The Massachusetts Home of Your Own Alliance will hold a conference for individuals with disabilities interested in being selected for two new programs for home ownership and expanded tenant control on Saturday, September 21, 1996 at the B.U. Conference Center, Tynsboro, MA. To request a brochure and registration form, call Citizens' Housing and Planning Association (CHAPA) at (617) 742-0820 after Sept. 1.❑

MENTAL ILLNESS AWARENESS WEEK
October 6-12, 1996

Two Research Centers of Excellence....

The Center for Psychosocial and Forensic Services at University of Mass Medical Center in Worcester and The Commonwealth Center at the Mass. Mental Health Center in Boston. The Department is funding these two centers for the purpose of bringing together some of the best minds and talent in Massachusetts to advance treatment and rehabilitation methods for chronic, persistent and severely psychiatrically ill patients. The Center at the University of Massachusetts Medical Center concentrates on Behavioral and Forensic Services. The Commonwealth Research Center focuses on Clinical Neuroscience and Neuropharmacology. Alan Green, M.D. and William Fisher, Ph.D., present an overview of the center with which each is associated.

Center for Psychosocial and Forensic Services Research

By William H. Fisher Ph.D., Director of the Center for Psychosocial and Forensic Services at University of Massachusetts Medical School in Worcester.

The Center opened in July 1993. Its primary mission is to conduct research that will help DMH maximize the effectiveness of services it delivers to people with severe mental illness and their families. The center also serves as a consultative resource to DMH administrators and providers.

The research is concentrated in five key areas. These include the Organization and Financing core, which conducts research on the effects of changes in the way services are delivered and financed, including managed care and state hospital downsizing. A second core, Child and Family Studies, looks at the delivery of mental health services to children and adolescents, the problems of individuals moving from the adolescent to the adult system, and special issues facing families that include individuals with severe mental illness. The third core, Forensic and Legal Issues, conducts research in two basic areas. The first concerns the way in which actual or potential legal interventions, such as outpatient commitment, can affect the way services are delivered. The second examines the use of the forensic mental health services within the Department of Mental Health and factors associated with people with mental illness involved in the criminal justice system. The fourth core, Psychosocial Rehabilitation Services, examines the effectiveness of programs based on rehabilitation models, such as clubhouses and transitional employment. The goal is to devise and evaluate methods used to enhance the functioning of individuals with mental illness and to maximize the extent that individuals can live and work independently. The fifth and final core area, Multicultural Studies, addresses providing mental health services to a population that includes a diverse array of ethnic, cultural and linguistic groups with different problems and service use patterns. This core examines these issues directly and provides a multicultural perspective for research carried out in the other areas.

Researchers at the center are faculty members in the Department of Psychiatry at the University of Massachusetts Medical School, drawn from a range of disciplines that include psychiatry, psychology, sociology, occupational therapy, and statistics. Faculty are assisted by a team of research associates and assistants, as well as an increasing number of students from Massachusetts colleges and universities who serve internships at the Medical Center as part of their undergraduate education. The Center of Ex-

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cellence also collaborates with researchers in several other academic and national research centers. The research center's faculty is also attempting to expand the domain of consumer-based research. Plans are under way to develop a "consumer research consultant" function to assist researchers in developing and refining research questions and methods in fields such as parenting and transitional employment, where traditional approaches may prove inadequate.

Since its inception, the research center has worked with DMH on a range of long-and-short-term studies to help administrators better understand how services can best be delivered, assess outcomes in a wide range of domains, and use data for planning services in a rapidly changing health care environment. ❑

Commonwealth Research Center

By Alan Green M.D.

The Commonwealth Research Center, a DMH-sponsored Center of Excellence affiliated with the Department of Psychiatry at Harvard Medical School is based at the Massachusetts Mental Health Center (MMHC) in Boston. The center's focus is clinical research on neurobiological aspects of severe mental illness; it aims to increase understanding of the causes and physiological basis of severe disorders and to improve the clinician's ability to optimally treat people with these disorders.

The center has launched an array of research studies — some with an inpatient phase, and others that are entirely outpatient in nature. The inpatient studies are undertaken at the Commonwealth Research and Evaluation Unit at the Massachusetts Mental Health Center, a 12-bed inpatient facility dedicated to intensive evaluation of patients and implementation of clinical research protocols. Outpatient studies are currently based at the MMHC and at the Brockton Multi-Service Center. Plans are underway to expand the outpatient research capability to other sites as well.

Since the research protocols and evaluation capability of the center are open to people from across the state, an outreach program has been started to ensure that those DMH clients and their clinicians residing in areas outside of Boston receive information about and have access to projects. Currently, the center is engaged in several clinical research studies utilizing up-to-date techniques of biochemical pharmacology, neuropsychology, neuroimaging and epidemiology:

1) Investigators are exploring experimental medications to treat psychotic disorders. Through this program, DMH clients have the opportunity to take some of the new generation of medications in carefully controlled research studies. In many cases, the medications used will not be available to the public for years; thus, DMH clients will benefit from early use.

2) Studies are under way on how to best use the atypical antipsychotic drug clozapine. It is clear that clozapine is a highly effective medication, but it is also clear that the drug has side effects that have limited its use to those who are refractory to other treatments. Studies at the center are trying to determine why clozapine is better than other medications and in what way it can be most optimally used.

3) Other studies are focused on leaning more about the symptoms of patients but also the overall levels of functioning — in terms of social interactions and work performance. One aspect of these studies involves careful assessment of cognitive functioning within trials of new therapies.

4) Family studies are under way to learn more about how severe mental illness is exhibited in families, so as to develop strategies to prevent disorders and develop early intervention models to minimize the long-term disabilities they produce.

An overarching theme for many of the studies involves attempts to improve the long-term trajectory of functioning of patients with severe mental illness. As an off-shoot, investigators are exploring ways to iden-

Continued on Next page

tify those at risk of psychotic disorders, with the hope that the onset of psychosis can be prevented.

DMH clients who participate in studies at the center receive excellent clinical evaluations and high quality clinical care, whether inpatient or outpatient protocols. Moreover, they have the opportunity to receive the most up-to-date treatments available. In future issues of this Bulletin, we will describe in detail some of the studies. Meanwhile, any DMH clinician who is treating persons with a psychotic disorder and who is interested in knowing whether the individual may be eligible to participate in a project may call Mr. Patrick Dooley at (617) 734-1300, ext. 215. Clients or family members are also encouraged to call the same number for information about the ongoing work at the center. ❑

Consumer-Run Initiatives 1996-1997

Consumer-Run Initiatives are a new and evolving reality. A primary reason for forming this project was the limitation of the service system, and the stigma attached to people with mental illness about their not being capable to be productive human being. Many consumers have often expressed that current mental health services alone are not enough to help them lead full lives in the community. Even in a perfect service system, a person who uses services is always viewed as a "client" or a "patient." We need to move beyond the traditional notion of services to accomplish two important roles:

* Supporting consumers in developing and running their own independent projects;
* Ensuring a clear and effective expression of consumers' own voices in changing and improving the mental health system

The goal of developing a base of consumer-run organizations which rely on the skills and talents of their members is not the same as funding traditional services

More mental health agencies are begining to hire consumers for existing jobs within the agency. While it is important for consumers to work in service agencies, it is equally important to support consumer-run programs.

INITIATIVE EXAMPLE:

Traditional Service Model: Staff starts and run a vocational rehabilitation service in which people are treated more as clients than as employees

Consumer-run Model: Consumers meet as equals and decide to start a business venture. They may seek out those with proven business expertise for advice and possible inclusion on a board or committee. Anyone who performd day-to-day management functions is accountable to the members. No one is treated as a client or a case. All people work together to make their business succeed in a competitive marketplace. Everyone has a say in how the organization is run.

Consumer-run funding is intended to provide the opportunity for people who have used the mental health system, to have their own organization. The common objective of all those involved in these projects is to improve the quality of life for themselves and other consumers. Through these projects consumers do work which is meaningful for themselves and which fill a need in their community. The complex nature of these projects has made it necessary to have skills consumers could tap into, at least for some, during the initial stage or throughout the project duration.

For this round of initiatives the Office of Consumer and Ex-patient Relations received a total of 47 proposals for funding, and 12 projects were funded for this year. ❑

Stigma a WorldWide Problem:

Vietnamerica: The War Comes Home, by Thomas Bass, is the heartbreaking story of children of American soldiers who were left behind after the fall of Saigon. Scorned in their mothers' country, many came to the United States under the Amerasian Homecoming Act of 1987, hoping to find acceptance and opportunity, but more often meeting with resentment and rejection. The Vietnamese government also saw the program as a way to rid itself of other undesirables. Bass writes, "The government scrapes up its riffraff, its schizophrenics and criminals and sends them to America."

The Long Shelf Life of Medical Myths: arthritis and the weather, acne and chocolate, hyperactivity and sugar, ulcers and stress, the common cold and wet feet, all medical myths that have crumbled under the scrutiny of science.

Most myths die when evidence actually leads to a cure, as in the case of ulcers which researchers found is caused by a strain of bacteria and can now be controlled with antibiotics. Still, some myths linger. Myths about mental illness are deeply rooted in our culture. People continue to believe that mental illness is caused by poor parenting or poor character, that there are no effective treatments, that mental illness is the same as mental retardation, that all people with a mental illness are violent. All myths, all untrue.

"Slouching Toward Ira," a May 22, 1996 Wall Street Journal editorial on providing equal coverage for mental illnesses in insurance plans, elicited three pull-no-punches responses from physicians. Melvin Sabshin, M.D., Washington, wrote, "This demonstrates clearly and disappointingly that the stigma surrounding mental illnesses thrives...why not limit insurance benefits for lung cancer and heart disease caused by cigarette smoking which is an individual choice...why not cut back on the billions of dollars we spend to treat low back pain suffered by those who choose not to exercise...how about limiting benefits for treatments, including transplants, for cirrhosis of the liver caused by alcohol abuse?" And Harold Bursztajn, M.D., Cambridge, Mass., advises, "It is time to address the pain, suffering, and economic costs of maintaining the prejudice of a mind-body dichotomy." William Weitzel, M.D., Lexington, Kentucky, notes, "Patients afflicted with serious mental disorders include more than those "poor souls described (uneducated, homeless, abandoned), but also people of accomplishment, such as Admiral Jeremy Boorda, Vincent Foster, and Margot Kidder," concluding, "Mental disorders can be diagnosed reliably; research-validated treatment interventions work; and together we can design an affordable process."

Does this surprise you?... In a recent study, respondents were asked to rate which disability groups were most/least acceptable to them. Those disability groups most acceptable were individuals with obvious physical handicaps; next came those who were blind or deaf. The least acceptable were ex-convicts, the retarded, and alcoholics. Placing last were the mentally ill.

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Briefly Noted...

Appointed Director of NIMH...Steven E. Hyman, M.D., an associate professor of psychiatry at Harvard Medical School and director of research in Massachusetts General Hospital's department of psychiatry, is the new director of the National Institute of Mental Health (NIMH), the leading agency for research on mental disorders. "Unlocking the mysteries of the brain and mental illnesses stands as the supreme challenge of biomedical science today," Hyman said of his appointment. Besides the opportunity to lead the Institute which is dedicated to translating scientific advances into new hope for the millions of Americans suffering from mental illness, Dr. Hyman sees another role for NIMH as well. "NIMH must also educate policy makers and consumers. All the evidence we have to date — and I look forward to even more - is that serious mental illnesses are real brain diseases and no different from stroke or brain tumor. There is absolutely no biomedical justification for separating out psychiatric disorders from other brain disorders. After all, we don't tell the families of patients with a brain tumor that they have limited lifetime coverage — how can we say that to families of patients with schizophrenia or manic-depressive illness?"❑

Myrellen's Coat: A Testimony to Courage...On a hot July day in 1948, a woman known as Myrellen, arrived at the door of Lakeshore Mental Health Institute in Knoxville,Tenn., after terrorizing her neighborhood and attacking her husband with a butcher knife. She spent the next 25 years at Lakeshore with almost no contact with the outside world. In the days before psychotropic medications, her therapy became embroidery. The coat she created was made from thread pulled from rags in the laundry. The pictures she weaved into the coat were the images that troubled her mind or stirred her memory. After the development of thorazine, she no longer sewed and even denied her handiwork. Years later, her coat was found in the sewing room and saved from the trash. Since 1983, Myrellen's coat has been shown throughout the country, including at the Smithsonian Institution in Washington, D.C. and was on exhibit at the National Alliance for the Mentally Ill Convention this year in Nashville.❑

Possible ECT Replacement... An international consortium of scientists was formed in June to study the use of magnetic brain stimulation in the treatment of depression. Until recently, magnetic brain stimulation has been used mainly to improve brain imaging in efforts to better understand and map the brain. However, a recent study in its clinical use showed a significant decrease in depression for 12 outpatients (11 men and 1 woman) who had a DSM-IV defined episode of major depression. There were no side effects and no dropouts. The procedure requires no anesthesia. To date, the confusion and amnesia associated with ECT have not been seen with magnetic brain imaging.❑

Bill Cosby and Alvin Poussant, M.D.,win Solomon Carter Fuller Award...given each year by the American Psychiatric Association to individuals whose contributions have significantly benefited the lives of black people. Poussant, a clinical professor of psychiatry at Harvard, is a founding member of the Black Psychiatrists of America and long time friend

and adviser to "The Cosby Show." Both men urged psychiatrists and mental health professionals to pay serious attention to the needs of low-income minority communities whose people think, Cosby said, "because the're poor, they can't have any mental health problems."❑

A recent study showed that of all health insurance policies in America, only 37% have in patient coverage for mental illness. On a $100,000 hospital bill, a medical patient pays about $3200 out-of-pocket, while a patient with mental illness pays $89,000 out-of-pocket for the same amount.❑

Even Hippocrates knew that a blow to the head can leave bruises on the mind. By studying the effects of brain injuries, he demonstrated that the mind is not centered in the heart, as romantics like to believe. It has taken centuries and the invention of brain-scanning to prove him right.❑

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"Schizophrenia is a disease that strikes at the very core of what makes us all human. As the cloud of schizophrenia moves across an individual's horizon, it introduces a barrier between that person and the capacity to experience warmth, to see and think clearly, and to feel and express feelings. The symptoms of schizophrenia run across the entire gamut of capacities that characterize human behavior, cognition and emotion, perception, thought, language, volition and creativity. The capacity to perform these functions well is often replaced by strange and terrifying internal perceptions and experiences. To an outsider, this is bizarre, frightening and off-putting. To the person with schizophrenia and his or her family, they are frightening and depressing. The combination of public misconceptions and ignorance with intense internal suffering makes schizophrenia perhaps the most tragic of human illnesses. Nancy Andreason, M.D. Ph.D., Schizophrenia: **From Mind to Molecule**, 1994.❑

NATIONAL DEPRESSION SCREENING DAY

OCTOBER 10, 1996

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Call Toll Free:

1-888-805-1000

Name_____
Address _____
City _____
State_____
ZIP_____
Telephone ( ) _____

Would you identify yourself (optional) as:

☐ **Consumer** ☐ **Family** ☐ **Provider**

Please list any specific interest in any of these area of mental illness:

1) ☐ **Housing**
2) ☐ **Employment**
3) ☐ **Education/Return to School/Supported Education Programs**
4) ☐ **Substance Abuse**

JOIN THE DMH BULLETIN?

We hope you have enjoyed reading our newsletter. We have a database (a sort of computerized telephone book) that allows us in a matter of seconds to retrieve people by specific areas of primary interest. If you aren't already on our mailing list or would like to be included we encourage you to fill this form and return it to us. Confidentiality is assured. We appreciate your interest, time, and enthusiasm.

5) ☐ **Medicaid, Medicare**
6) ☐ **Clubhouse**
7) ☐ **Advocacy on State Budget & Legislation**
8) ☐ **Parent of a child with serious emotional disturbances**
9) ☐ **SSI/SSDI**
10) ☐ **Welfare Reform**

Interested in becoming involved in the local service system planning?

BREAKDOWN OF NATURAL SERVICE AREAS & WHOM TO CALL

WESTERN MASS.
James Duffy,
Area Director
413-584-1644
1 Central/South Berkshire
2 Franklin/North Quabbin
3 Hampshire
4 Holyoke/Chicopee
5 North Berkshire
6 Springfield
7 Westfield

NORTHEAST
Lorene Bourque,
Area Director
508-851-7321
1 Beverly
2 Greater Lawrence
3 Greater Lowell
4 Haverhill/Newburyport
5 Lynn
6 Wakefield

METRO WEST
Theodore E. Kirousis,
Area Director
508-792-7400 ext. 2073
1 East
2 West

CENTRAL MASS.
Constance P. Doto,
Area Director
508-752-4681 ext. 263
1 Milford
2 Southbridge
3 Gardner
4 Fitchburg
5 Worcester

METRO SOUTH
Barbara A. Leadholm,
Area Director
508-359-7312 ext.600
1 Newton/South Norfolk
2 South Shore/Coastal

SOUTHEAST
John P. Sullivan,
Area Director
508-580-0800 ext. 201
1 Brockton
2 Cape Cod
3 Fall River
4 New Bedford
5 Plymouth
6 Taunton/Attleboro

METRO-BOSTON
Clifford Robinson,
Area Director
617-727-4923 ext. 301
1 Bay Cove
2 Cambridge/Somerville
3 Lindemann
4 Mass. Mental Health Center
5 Solomon Carter Fuller

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The DMH Bulletin

Massachusetts Department of Mental Health Vol. 1 No 6 FALL 1996

CAP to be Outlined at National Conference

By Julia Meehan

The Collaborative Assessment Program (CAP), a Southeastern Area pilot project providing a single point of entry for seriously emotionally disturbed youth at high risk of out-of-home placement, will be discussed at a national conference March 13-17 sponsored by the Trieschman Center in Needham. The presentation, which will take place at the Hyatt Regency in Cambridge, is part of a program entitled, "What Works with High-Risk Youth and Their Families? Cost Effective Practices and Measurement Tools."

The Department of Mental Health has worked with the Department of Social Services and the Division of Medical Assistance to conduct timely and comprehensive assessments for children and families, provide a coordinated and integrated planning effort, and offer support structures to families during assessments -- stabilization, intensive case management and the immediate application of direct services.

In addition to completing family and child assessments, the program makes eligibility determina-

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From the Commissioner

Mental Health Parity Legislation: A Good First Step

By Marylou Sudders

As nearly every consumer, family member, legislator and care giver knows, the health care environment is in a state of flux. When and where it will settle remains uncertain. One of the concepts affecting the changing climate concerns mental health parity.

A recently enacted federal law represents the first step in tackling a long-standing discriminatory practice which stated that individuals with serious mental illness cannot have the same medical insurance benefits as people with other biological disorders.

This less than full parity amendment to an appropriations bill emerged out of Congress requiring insurance companies to offer the same level of coverage for mental illness as they do for other physical illness. It specified that aggregate and annual payment limits be the same. For example, if an insurance plan has a $1 million lifetime spending limit for medical treatments, it cannot limit spending on mental health to $50,000.

Under the amendment, insurance premiums will rise only an estimated 0.4%, according to the Congressional Budget Office.

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tions for DMH and DSS within 21 days. Historically, a family with child welfare and mental health needs was required to approach each agency and go through two 45-day assessments. They were often asked to produce the same information and respond to the same questions at each intake.

The process is now streamlined; the outcome usually involves a transfer to either DMH or DSS for appropriate care. It also includes a referral to a "Parent Partner," who not only provides support and advocacy for parents, but continues to work with the family after CAP has referred them to either DSS or DMH.

A total of 56 children were processed through the CAP during FY'96. The profile of the CAP population and the comparison group finds that the average age at referral was 14. When referred, 33% of the youth were in psychiatric hospitals and 33% resided at home. The remaining third were in crisis programs. A total of 90% of all children referred had at least one psychiatric hospitalization. Principle reasons for referral included assaultive and impulsive behavior (40%), suicidal/homicidal tendencies (20%), and families unable to manage children (30%).

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The DMH *Bulletin*

A quarterly Publication of the Massachusetts Department of Mental Health, reporting state news and relevant information for consumers and their families, mental health professionals, vendors of services, and all citizens interested in the goals and mission of this Human Service Agency

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Mental Illness is Protected Under ADA

Where mental illness was limited under a disability insurance policy to only two years whereas physical illness was covered until age 65, this might violate the Americans with Disabilities Act, says the United States 6th Circuit Court. The employer will be allowed to sue the insurance carrier. This opinion could also be good news for plaintiffs seeking coverage for other categories that are often excluded, such as experimental cancer treatments, AIDS, etc.--- *Lawyers Weekly.*

Department of Mental Health Training Event

Date	*Title*	*Sponsoring Area*	*Contact*	*Phone Number*
12/19/96	Needs & Rights of the Deaf & Hard of Hearing	Western Mass.	Harry Weinmann	413-584-1644

(CAP) Continued from Previous Page

An initial study of CAP participants conducted last Spring, comparing them to children and families not involved in CAP, showed that children involved in the program were less likely to be hospitalized during and after the assessment process. Those that were hospitalized had shorter stays -- between 60-79% less. When it came to recommended placements after assessment, children in the CAP process were more likely to return home to reside with parents or relatives with appropriate community services 80% of the time. Meanwhile, the comparative group returned home only 30% of the time. A total of 57 creative services were recommended for children in the CAP program who remained in the community; only 15 distinct services were used for children in the community in the comparative group.

The study, which was conducted last Spring, consisted of a small sample size (n=10) due to start-up. CAP, which replaced the Executive Office of Health and Human Services Out-of-Home Placement Project and targets the same group, is now in its second year.

Although it is apparent that the program must be studied for a longer period to draw conclusions, most parents have praised the assessment process. Parents interviewed have found the assessments thorough, comprehensive and timely. They termed the CAP staff "caring, supportive and competent." Involving a Parent Partner who understands what it is like to cope with a child with serious emotional disturbance is a priority.

Currently, DMH and DSS are hoping to expand the project. For more information on CAP, contact me at the Southeastern Area Office - 727-7905, ext. 285, or Marge Waite, CAP coordinator, at (508) 946-5548. We will be joined by Christina Joyce, DSS program coordinator in Brockton, and Donna Wells, DMH parent coordinator, in presenting findings at the Trieschman Center conference.❑

Julia Meehan is Director of Child/Adolescent Services in Brockton, Plymouth & Cape Cod & Islands.

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The amendment, which became law when President Clinton signed the overall bill on September 20, falls well short of full parity because it does not require equality in inpatient days and outpatient treatment limits. It is a move in the right direction, however.

Make no mistake, there are loopholes. As The Boston Globe pointed out in an editorial endorsing the new law, "if insurance companies really want to keep their costs down, they can excise mental health coverage altogether or limit the number of hospital days a patient is allowed" ... or scale back other benefits ... or increase employee co-payments ... or combine medical and mental health under an aggregate spending cap, which would raise the limit for mental health only by lowering the pool of funds available for medical care.

Full parity will save $5.5 billion in mental health costs from lower public sector expenditures and greater private sector market efficiencies, according to studies done by nationally recognized actuarial firms.

Resistance to full parity is based on the incorrect premise that unlimited benefits in an outpatient, fee-for-service environment would result in increased utilization. It stemmed from an analysis estimating non-discriminatory coverage for mental illness would drive up insurance premium rates from 8.3% to 11.4%; it disregarded the prevalence of managed care altogether.

A later study for a group of mental health organizations showed full parity would result in a 3.2% increase in rates. This would have added about $5 to co-payments for outpatient visits and prescription drugs or a yearly deductible of $35 to $40.

New Hampshire, Maine, Rhode Island, Maryland and Minnesota have full mental health parity laws. There has been no hue and cry about

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Brain Research: From Knowledge Will Come a Cure

I am engaged in research at Harvard Medical School where I am studying the biological basis of mental illness. I have a brother who has been diagnosed with schizophrenia. Because of the stigma attached to mental illness and the serious shortage of brain tissue available for research, several of my colleagues openly discouraged me from dedicating my career to the study of mental illness. However, on account of my brother's experience, I have ignored these warnings and have openly embraced the challenges that this field of research offers.

By Jill Bolte Taylor, Ph.D.

The human brain is a highly complex and delicately balanced organ responsible for integrating diverse information from our environment and generating complex behaviors, such as reason and emotion. This daunting activity is accomplished through vast communication networks that are a function of an underlying substrate of brain cells and chemicals.

One of the great mysteries about the brain is how these various elements are affected in mental illness. To learn more about the origins of mental illness, laboratories throughout the world are looking to identify its various neurobiological substrates in brain tissue of people who have died.

One of the best kept secrets in Massachusetts is the existence of the Harvard Brain Tissue Resource Center ("Brain Bank") at McLean Hospital. The Brain Bank acquires, processes and stores human brain tissue for distribution to qualified scientists throughout the country. Only a few federally funded brain banks exist nationwide and the largest and most renowned is located in Belmont, Massachusetts!

The Harvard Brain Tissue Resource Center currently collects nearly 300 brains a year from individuals suffering from major neurobiological disorders, including Alzheimer's, Parkinson's and Huntington's diseases. The ability of the Brain Bank to make large numbers of these specimens available for scientific study has helped to foster increased interest in these diseases and has encouraged researchers to direct their energies to the study of these major brain disorders.

Unfortunately, severe mental illnesses, like schizophrenia, manic-depressive illness and depression, have not received comparable public and scientific attention. This inequity is due, in large measure, to a long standing shortage of brain tissue donated from individuals diagnosed with severe mental illness. In the 15 years that the Harvard Brain Tissue Resource Center has been up and running, there have been fewer than 10 brains a year donated from individuals with severe mental illness. You may be surprised to learn that fewer than one such brain each year has been donated by Massachusetts residents with severe mental illness. With the current rate of donation in the U.S., only a handful of laboratories can be supplied with this precious tissue.

Modern brain imaging technologies, including magnetic resonance imaging (MRI), positron emission tomography (PET) and computed axial tomography (CAT) are yielding important new information concerning the structure and function of the human brain. However, a complete understanding of the underlying "hard wiring" differences responsible for psychotic behavior can only be fully realized with postmortem studies that compare the fine microcircuitry of "healthy" and "mentally ill" individuals.

Becoming a prospective tissue donor is simple. Any person at least 18 years of age or older may preregister for brain donation. In all cases, the identity of each donor and potential donor is con-

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ON THE ROAD TO PREVENTION

The words "prevention" and "cure" are not common currency in the world of mental illness, but more and more, they are beginning to be heard:

■ In a five-year study, researchers at Massachusetts General Hospital and Harvard University aim to identify ways to block the development of panic disorder, agoraphobia and depression, all conditions that tend to run in families. The prevalence of these disabling disorders is high (millions of Americans) and their cost to society even higher. The possibility of early intervention is welcome news. For more information, contact the Child Study Center at Massachusetts General Hospital at (617) 726-5000, ext. 133-1033.

■ *International Approaches to Prevention in Mental Health and Human Services,* edited by Robert E. Hess, Ph.D., and Wolfgang Stark, 1995. Hess, from the United States, and Stark, from Germany, have assembled articles for this slender volume from authors in eight countries. The contributing authors describe a variety of projects, such as community empowerment in Costa Rica, informational programs for Korean immigrants in the U.S., and self-help groups in Denmark. Several chapters describe the success of specific programs funded under legislation passed by governments interested in preventing mental illness and willing to increase funding (Canada, Italy, the Netherlands.) This book has broad appeal, but should be of special interest to clinicians and administrators in public and private institutions and mental health agencies.

■ According to *Psychiatric News* (July 1996), "the course of schizophrenia can be improved through early identification and intervention." Since the time when schizophrenia was first defined by Kraeplin a hundred years ago, physicians have been treating patients after the onset of psychosis, seeing only the end result of a process that Kraeplin believed began much earlier. A growing body of evidence now suggests the possibility of early intervention. Thomas McGlashan, M.D., wrote in the *Schizophrenia Bulletin*, volume 22, 1996, "I have had the pleasure of helping many patients with schizophrenia in my professional career and have seen clear advances in the understanding and treatment of the pyschoses, so I remain optimistic. But I am convinced that with most of my patients, I came upon the scene too late; most of the damage was already done. Our current treatment efforts amount to palliation and damage control. For many vulnerable to schizophrenia, the ultimate answer lies in early detection and preventive intervention."

■ *THE ECONOMIC$ OF TREATMENT...* Beyond ushering in hope against the vast personal devastation wrought by schizophrenia, the new atypical antipsychotic agents may lighten some of schizophrenia's crushing financial burden. The U.S. tally for schizophrenia treatment and care now stands at a staggering $65 billion a year in combined direct and indirect costs, according to Richard J. Wyatt, M.D., chief of neuropsychiatry for the National Institutes of Mental Health (NIMH). At this year's annual meeting of the American Psychiatric Association, Wyatt expressed hope that in the future, individuals with early symptoms, but without full-blown schizophrenia, can start drug therapy before the illness has had a chance to take its toll. ❑

Two Research Centers of Excellence....

The Center for Psychosocial and Forensic Services at the University of Massachusetts Medical Center in Worcester and The Commonwealth Research Center at the Massachusetts Mental Health Center in Boston are funded by DMH. They bring together some of the best minds and talent in Massachusetts to advance treatment and rehabilitation methods for chronic, persistent and severely psychiatrically ill patients. The Center at the University of Massachusetts Medical Center concentrates on Behavioral and Forensic Services. The Commonwealth Research Center focuses on Clinical Neuroscience and Neuropharmacology. Alexis D. Henry, ScD, OTR/L, presents a feature on clubhouses and transitional employment; Alan Green, M.D., presents a feature on the effects of clozapine.

Examining Outcomes of Clubhouse-Based Transitional Employment

By Alexis D. Henry, ScD, OTR/L

The unemployment rate for individuals with persistent mental illness has been estimated as high as 85 percent. Studies have shown that developing appropriate vocational skills is key to any psychosocial rehabilitation program for these clients.

One psychiatric rehabilitation program that has helped people with mental illness gain employment involves the clubhouse movement. It originated with Fountain House in New York City in 1948. According to the International Center for Clubhouse Development, 310 psychosocial clubhouses exist worldwide; there are more than 205 in the United States, with 27 in Massachusetts.

Transitional Employment Programs (TEPs) are an integral part of the vocational programming at each clubhouse. TEPs provide supported, time-limited, competitive employment experiences for clubhouse members. The goals of Transitional Employment Programs include developing vocational self-confidence, work adjustment skills, and work experience to facilitate movement to more permanent employment. Although moving to independent employment is the ultimate goal of transitional employment, few studies have evaluated the success of these programs in achieving this objective.

In collaboration with Genesis Club in Worcester and Employment Options in Marlboro, the Center for Psychosocial and Forensic Services Research is conducting two studies looking at employment outcomes of individuals participating in transitional employment placements.

The first is a retrospective study of 139 Genesis Club members who participated in transitional employment from July 1988 to July 1995. Records from both clubhouses were used as the basis of this study. An analysis is not yet complete, but preliminary results show that in the year after their final temporary employment placement, 29.3% of the members had attained permanent employment. This percentage increased to 46.4% when longer follow-up periods were examined (up to 7 years after TEPs). The members who were more likely to be permanently employed after temporary employment were those who had participated in more TEP placements, had worked more days a week while on a TEP assignment, had more education, and were older.

The second study is a longitudinal, prospective follow-up of Genesis Club and Employment Options members currently participating in Temporary Employment Programs. After entering the study, members will be checked at six-month intervals until 24 months have elapsed, and then yearly until the 48-month mark. The study involves collecting more detailed baseline data regarding temporary employment experiences, psychiatric history, prior work history, vocational goals and perceptions concerning work competence. At the follow-up points, information on employment, readmis-

Turn to (Clubhouses) on Next Page

Clozapine Research May Open Windows to New Studies

By Alan I. Green, M.D.

Clozapine has proven to be more effective than many of the standard antipsychotic drugs and opens the window for exciting new studies concerning better treatment for people with psychotic disorders, according to our research at the Commonwealth Research Center (CRC) at the Massachusetts Mental Health Center and at other research centers around the country.

The standard or "typical" antipsychotic drugs were introduced into clinical practice in the 1950s and became the mainstay of treatment for psychotic disorders. Although the drugs are highly effective, there are problems associated with them. They do not provide a "cure." Some patients respond to these medications and then relapse and some patients do not respond at all. Among those who do respond, there may be side effects (especially related to the control of physical movements) that limit their use.

"Typical" antipsychotic drugs block one of the receptors for dopamine, a brain chemical. Until recently, most people working in the field believed that blocking the dopamine D 2 receptor was required for all medications that might have potential antipsychotic impact. While the new antipsychotic drug clozapine -- an "atypical" antipsychotic medication -- apparently blocks this chemical dopamine D 2 receptor, it does so weakly. Therefore, clozapine is a paradox: It is the most effective antipsychotic drug available, but it does not seem to work through the mechanism long thought to be the basis of antipsychotic drug action.

These unusual characteristics of clozapine have peaked the interest of researchers. Briefly put, research findings have concluded that clozapine appears to work on several brain chemical systems in addition to dopamine -- including serotonin and norepinephrine. Moreover, clozapine has the unusual ability to increase the action of the chemical dopamine, rather than blocking it, in some areas of the brain. Why clozapine increases dopamine's action is unclear; it may be related to its interaction with other brain chemicals.

Ultimately, the fact that clozapine increases dopamine action in some areas of the brain allows it to shut it down in others. Put another way, its ability to decrease dopamine in some areas of the brain -- where psychosis is generated -- appears to stem from its ability to increase dopamine action elsewhere.

This unusual spectrum of actions on dopamine gives clozapine its unique clinical profile. Moreover, researchers at the Commonwealth Research Center also believe that clozapine's spectrum of actions suggests it could have a long-term impact on people with psychotic disorders -- longer than the "typical" drugs.

As a result, the center has launched a study to determine if the early use of clozapine in treating schizophrenia would improve the long-term, positive outcome for the patient. Because of its side effects, clozapine is used only with individuals who do not respond to other medications. But, if this CRC study shows that clozapine is safe for "first episode" clients and can also improve their long-term outcome, then the way it is now clinically used should be reassessed.

Experimental use of clozapine in "first episode" patients with schizophrenia is only one aspect of an early intervention strategy currently being studied at the Commonwealth Research Center. If any reader would like to refer a potential ""first episode" patient to one

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sions to hospitals, functioning and life satisfaction data will be collected.

Fifty individuals have been recruited for the study to date. Data from the first six-month follow-up period are currently being analyzed, and preliminary results may be available by the end of November. During the next year, an additional 50-60 individuals will be added to the study. ❑

Alexis D. Henry is an Assistant Professor of Psychiatry at the Center for Psychosocial and Forensic Services Research at the University of Massachusetts Medical School in Worcester.

MASSACHUSETTS PRIDE IN PERFORMANCE RECOGNITION PROGRAM

For the past 12 years, state employees have been recognized at a special awards dinner honoring their exemplary performance in the work place. This year's dinner took place on Thursday, October 3, at the Sheraton Boston Hotel where Governor William Weld delivered the keynote address.

Fifteen Department of Mental Health employees and groups, including support, clinical and managerial staff, received Commonwealth Citations for Outstanding Performance. Some of the comments used by fellow employees to describe their work were "professional;" "compassionate," and "creative." All contributed toward significant improvements in delivering services and in improving operations.

Among the DMH employees receiving this year's Pride in Performance Awards at the Sheraton Boston Hotel were: (from left, top) Naomi Diamond, Metro Boston Area; Elaine Hill, Forensic Programs, with DMH Commissioner Marylou Sudders; Geraldine Marks, Central Mass. Area; (from left, bottom) Elaine Braley, Northeast Area; Lauren Meese Lucove, Metro West Area; Jeff Bianchi, Southeast Area; Ursula Macmillan, Central Office.

SCHOLARLY SILVER, (Harvard Magazine, May - June 1996) ... Every year, during commencement week, a silver pitcher and goblet grace the speakers' table at the annual Phi Beta Kappa meeting. The silver was given to Harvard in 1892 by Sarah Wyman Whitman, in the name of her brother, Charles Wyman, A.B. 1867, "to be used by the University on public occasions in Sanders Theatre." An artist who worked in many mediums, she designed the silver herself and had it made by Shreve Crump & Low. Charles Wyman spent most of his life in a mental hospital and it is thought that the silver may have been Sarah's way of marking his 25th reunion year. What courage it must have taken in 1892 to go public about mental illness in the family. Today, when the stigma of mental illness is just beginning to be addressed, this brave gesture, made by a loving sister so long ago, reminds us of the great loss mental illness causes to individuals, their families and to the community.

STIGMATIZING LANGUAGE ON THE HORTICULTURAL PAGE... Just as styles in fashion change, so do plants come and go in the garden. Petunias and geraniums cede space to impatiens and day lilies. Currently called back from the compost heap, according to the New York Times (9/8/96), is the colorful coleus. Its dappled leaves have evoked many lyrical names, including "Dark Star," "Thumbelina," "Radiance," "Gold Spun," and "Schizophrenia." Schizophrenia? A plant named for an illness? Only in a world that does not understand that schizophrenia is a brain disorder.

THERAPIST'S LESSONS LEARNED AS A PATIENT... Clinical psychologist and author Martha Manning, Ph.D., would have been delighted to receive her knowledge of severe depression, medications, ECT and life on an inpatient unit from her clinical training instead of personal experience. In her book, *Undercurrents: A life Beneath the Surface,* she describes "an eternity of sorrow called severe depression." Referring to the stigma attached to mental illness, she says she would not have published her book if she "was climbing a tenure track or scaling the heights of an administrative position." Manning has received the American Psychiatric Association's 1996 Patient Advocacy Award.

THE GOOD NEWS DEPARTMENT... Newt Gingrich: House Speaker, powerbroker and stigma buster?...After receiving criticism from advocates for the mentally ill, the Georgia congressman agreed to delete two references offensive to people with mental illness from his book, *To Renew America.* "Convicted felons and the mentally ill," has been changed to "persons who have committed crimes."

HALLOWEEN SCREAM HEARD AGAIN... In the Fall of 1995, the DMH Bulletin reported that the costume shop, Halloween Scream, at Meadow Glen Mall in Medford was featuring an outfit that said, "PROPERTY of STATE MENTAL HOSPITAL." A complaint was made at the time and the shirt was removed from the window display, but this year it appeared again, this time in the Halloween Scream shop at the Hanover Mall. Phyllis Burns and John Bove of the Plymouth Alliance for the Mentally Ill alerted salespeople at the shop and the management of the Mall and the shirt was put away. Burns is currently tracking down the manufacturer of the shirt.❑

Boston State Hospital Commemorated as Pioneer in Continuing Care

The life and times of patients and staff at Boston State Hospital were traced as part of a special commemorative exhibit and display recently in the Great Hall of the State House.

The historical tribute included former patients, family members and staff from the days when the hospital was the focal point for long-term mental health care in metropolitan Boston. The November 21 exhibit was part of activities kicking off a long-term project entitled, "Boston State Hospital, 1839 to 1996: Continuing Care, the Key to the Future."

The exhibit showcased mounted quotations from those associated with Boston State, a historical display of artifacts, including photographs, and a replica of a furnished patient's room that depicted what it was like to be treated, visit and work at the hospital. There was a narrated slide show and visitors heard tape recorded conversations with people who recall their days at the long-shuttered hospital.

The exhibit traced the evolution of today's public mental health system.

"A brief look at Boston State Hospital reveals major developments in the field of mental health care," said DMH Commissioner Marylou Sudders. "The hospital dates to 1839 when the Boston Lunatic Hospital was opened in the area known as Dorchester Neck, the current site of the Edison power plant in South Boston. The hospital primarily served the indigent population of people with mental illness who had been imprisoned and in alms houses before the hospital was built."

In 1892, the site most recently known as the state hospital campus was developed on the Austin and Pierce farm lands. In 1908, the country's first municipal institution constructed to house and treat people with mental illness was turned over to the state. The state paid the City of Boston $1 million for the more than 230 acres of land and buildings and renamed it Boston State Hospital.

In 1912, Boston Psychopathic Hospital was created as part of Boston State. It represented another first in public mental health care. Boston Psychopathic was the country's first diagnostic and treatment facility designed to focus on observation, research and treatment of the acute mentally ill. By December of 1980, all but one building was shut down. In July 1981, the campus administrator locked the Barton building for the last time.

Other speakers at the exhibit included Charles D. Baker, Secretary of the Executive Office of Administration and Finance, Senator Dianne Wilkerson, Representative Shirley Owens-Hicks, Cliff Robinson, Metro Boston Area Director, Dr. Jonathan Cole, a former Superintendent at Boston State Hospital, and Judith Zeramby of Community Friends of Boston State Hospital.

The Department's exhibit marked the first of three Boston State Hospital observances and activities during late November. The Division of Capital Planning and Operations marked the beginning of building demolition on the Boston State grounds with a formal program November 22. During the next nine months, most of the 29 buildings will be demolished, clearing the way for a complete remaking of Boston's largest undeveloped space. An 18-acre parcel will be developed as housing and about 900,000 square feet of mixed use development will be created for light manufacturing, commercial office, assisted living residential, housing, neighborhood retail and institutional uses. A total of 15% of the housing and 10% of the employment will be set aside for people with mental illness.

On November 23, the Alliance for the Mentally Ill of Dorchester, Mattapan and Roxbury sponsored a tribute to people with mental illness. ❑

(Brain) Continued from Page 4

fidential. Brain donation is not disfiguring in any way, and will not interfere with an open casket or other traditional funeral arrangements. Brain donation does not conflict with most religious perspectives. For clarification, please call for a copy of our brochure entitled, "Religious Perspectives About Donation."

To obtain more information or to initiate the process of brain donation, call 1-800-BRAINBANK (1-800-272-4622). A Brain Bank representative is on call 24-hours-a-day and will help make arrangements for the removal and shipment of the brain specimen.

Please join the growing movement to educate families and friends of those who have debilitating mental disorders about the critical importance of brain donation. Only families with mental illness can donate brain tissue for research into serious mental illness. This is something we can do together to help scientists unravel the mysteries of the human brain. Remember: " From knowledge will come a cure." ❑

Jill Bolte Taylor, Ph.D., is a Director of the Harvard Brain Collection and a board member of the National Alliance for the Mentally Ill.

(Parity) Continued from Page 3

staggering commercial premium rate increases in these states.

Costs are important; fairness is paramount. It is time to end discrimination by removing artificially imposed insurance coverage caps for mental illness.

In Massachusetts, Representative Angelo Scaccia has filed a mental health parity bill. Legislators should be encouraged to sign on so we can have the debate here. I hope you will join me in the fight to end insurance discrimination for people with mental illness. ❑

(Clozapine) Continued From Page 7

of our studies, please call Patrick Dooley at (617) 734-1300, ext. 215. Moreover, for further information about the strategy of early intervention with patients with psychotic disorders, please write to the Commonwealth Research Center, Massachusetts Mental Health Center, 74 Fenwood Road, Boston, Ma. 02115. ❑

Alan Green, M.D., is Associate Professor of Psychiatry at Harvard Medical School.

Name_____
Address _____
City _____
State_____
ZIP_____
Telephone ( ) _____
Would you identify yourself (optional) as:
☐ **Consumer** ☐ **Family** ☐ **Provider**

Please list any specific interest in any of these area of mental illness:
1) ☐ **Housing**
2) ☐ **Employment**
3) ☐ **Education/Return to School/Supported Education Programs**
4) ☐ **Substance Abuse**

JOIN THE DMH BULLETIN?

We hope you have enjoyed reading our newsletter. We have a database (a sort of computerized telephone book) that allows us in a matter of seconds to retrieve people by specific areas of primary interest. If you aren't already on our mailing list or would like to be included we encourage you to fill this form and return it to us. Confidentiality is assured. We appreciate your interest, time, and enthusiasm.

5) ☐ **Medicaid, Medicare**
6) ☐ **Clubhouse**
7) ☐ **Advocacy on State Budget & Legislation**
8) ☐ **Parent of a child with serious emotional disturbances**
9) ☐ **SSI/SSDI**
10) ☐ **Welfare Reform**

Interested in becoming involved in the local service system planning?

BREAKDOWN OF NATURAL SERVICE AREAS & WHOM TO CALL

WESTERN MASS.
James Duffy,
Area Director
413-584-1644
1 *Central/South Berkshire*
2 *Franklin/North Quabbin*
3 *Hampshire*
4 *Holyoke/Chicopee*
5 *North Berkshire*
6 *Springfield*
7 *Westfield*

NORTHEAST
Lorene Bourque,
Area Director
508-851-7321
1 *Beverly*
2 *Greater Lawrence*
3 *Greater Lowell*
4 *Haverhill/Newburyport*
5 *Lynn*
6 *Wakefield*

METRO WEST
Theodore E. Kirousis,
Area Director
508-792-7400 ext. 2073
1 *East*
2 *West*

CENTRAL MASS.
Constance P. Doto,
Area Director
508-752-4681 ext. 263
1 *Milford*
2 *Southbridge*
3 *Gardner*
4 *Fitchburg*
5 *Worcester*

METRO SOUTH
Barbara A. Leadholm,
Area Director
508-359-7312 ext.600
1 *Newton/South Norfolk*
2 *South Shore/Coastal*

SOUTHEAST
John P. Sullivan,
Area Director
508-580-0800 ext. 201
1 *Brockton*
2 *Cape Cod*
3 *Fall River*
4 *New Bedford*
5 *Plymouth*
6 *Taunton/Attleboro*

METRO-BOSTON
Clifford Robinson,
Area Director
617-727-4923 ext. 301
1 *Bay Cove*
2 *Cambridge/Somerville*
3 *Lindemann*
4 *Mass. Mental*
5 *Solomon Carter Fuller*

The DMH *Bulletin*
25 Staniford St.
Boston Ma. 02114

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Address Correction Requested

The DMH Bulletin

Massachusetts Department of Mental Health Vol.1 No 8 WINTER 1997

PARITY for MENTAL HEALTH COVERAGE...WHAT DOES IT MEAN?

A federal law, which will go into effect in January, applies only to employers and insurers who choose to offer mental health in their benefits plans. It does not require them to do so. Also exempt are all businesses employing fewer than 50 people.

What the law does:

- Insurance carriers who offer mental health coverage must provide the same annual and lifetime payment caps for treatment of mental illness as they provide for physical illnesses requiring medical or surgical intervention.

What the law does not do:

- Insurers are not required to cover mental health. Carriers are free to drop coverage altogether if they choose.
- The law will not change the maximum number of covered inpatient or outpatient visits. Plans may reduce or increase the number of covered visits as they deem appropriate.
- The law does not apply to coverage related to alcohol or drug addiction.
- There is no restriction on co-payments or deductibles. Companies are free to adjust either to offset costs.
- Businesses employing fewer than 50 people are exempt from the law as are those that can demonstrate a greater than 1% increase in costs.❑

From the Commissioner

$3M Budget Increase Sought for Homeless Mentally Ill

By Marylou Sudders

Winter usually prompts people to think more about the homeless in shelters and on the streets. The media runs stories concerning increases in the numbers of folks in need, shortages of shelter beds and what can be done to help individuals survive in bitter temperatures.

The problem is far from seasonal, however.

During the past seven years, DMH has operated a special initiative for the homeless mentally ill and $14.1 million is currently allocated in state funds for Boston, Quincy, the Lower Cape, Greater Springfield, Worcester, Pittsfield, Greater Malden, Lynn, Salem, Peabody and Gloucester. This has paid dividends.

Through this initiative, more than 600 people

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with mental illness who are homeless are served and housed. An additional 200 mentally ill people who are homeless will be helped through other DMH efforts. This adds up to services for more than 800 people. Forty-six more units of housing for the homeless mentally ill will be on line by July 1.

Governor Weld's House I budget submission calls for a $3 million increase in funding to serve an additional 325 homeless mentally ill people in FY'98. If the Legislature approves, state funding would total $17.1 million annually. The Massachusetts Housing and Shelter Alliance and the Department are working closely to secure these additional resources.

State dollars are used to provide outreach, treatment, and support services delivered before, during and after arranging suitable housing. In addition, the Department and its partners leverage housing resources from federal and other state sources — more than $16 million to date, largely from HUD McKinney and Section 811 programs — and develop partnerships with local housing authorities, municipalities and community-based housing groups.

A 1992 report estimated there were 8,957 homeless adults in Massachusetts, with up to 5,921 in Metropolitan Boston. Approximately 2,000 of the total had a severe or persistent major mental illness; 1,200 were in the Boston area; and 1,150 individuals had co-occurring substance abuse disorders.

DMH clients need appropriate support services so they are less vulnerable to eviction and homelessness. To improve coordination of service delivery, area offices are establishing formal service linkages, including development of affiliation agreements with local housing authorities.

The DMH inpatient discharge policy also is aimed at preventing homelessness. Clients are helped to find appropriate, permanent housing as part of discharge plans.

Enhanced discharge protocols for clients in the Metro Boston Area, which has the highest number of homeless mentally ill people in the state, are in place. A homeless outreach service that monitors the discharge process and identifies supportive housing options for clients operates within Boston. All individuals discharged from state-operated facilities and acute care inpatient units participate in individual service planning, including determination of residential and support needs and eligibility for entitlements.

DMH also sponsors other projects aimed at providing clients with appropriate support services designed to avoid homelessness.

A pilot project at six locations, which funded service coordinators on site at local housing authority developments for the elderly and disabled, was expanded through legislation to nine additional housing authorities in 1995. This program uses on-site field managers who work daily with all residents and refer mental health clients in need.

The same legislation is funding an alternative housing voucher program. It provides up to 800 rental subsidies to younger people with disabilities who are on waiting lists for state-aided public housing. Of these 800 vouchers, 15% are allocated to younger people with disabilities currently living in state-aided developments for the elderly and disabled.

The Path Program, supported by a grant from the federal Center for Mental Health Services, continues to underwrite the costs of clinical social workers across the state who provide direct care, housing advocacy and assistance as well as referrals for job training, literacy education, mental health services, and substance abuse treatment. The program is augmented by a HUD grant to Tri-City Community Mental Health and Retardation Center for outreach services. The program has been further expanded through a $550,000 initiative funded as part of a HUD McKinney application.

Can more be done? Absolutely. The key is legislative support and leveraging more HUD dollars. The case is being made on both fronts. ❑

THE BRAIN/BODY CONNECTION in the NEWS

Medication and meditation, acupuncture and aromatherapy, exercise as antidepressant, gene research and cognitive therapy... all are subjects of scientific study in the haze of the Mind/Body connection. Last December, nearly 1,000 health care professionals met in Boston for the second annual "Spirituality and Healing in Medicine" at Harvard Medical School. "I am not a religious person," said Dr. Herbert Benson, founder of the Mind/Body Institute at the Deaconess Hospital and a Harvard medical professor. Benson, author of The Relaxation Response, admits, "I came to this not from belief, but from science. Honestly, I came to this with feet dragging."

All this attention to the brain is good news for people with brain disorders. Dr. Steven E. Hyman, director of the National Institute of Mental Health warns, "the old mind-body distinction does nothing but get in our way." Professionals and the public are beginning to understand it.❑

The DMH *Bulletin*

A quarterly publication of the Massachusetts Department of Mental Health, reporting state news and relevant information for clients and their families, mental health professionals, vendors of services, and all citizens interested in the goals and mission of this Human Service Agency.

Write to us at:
"The DMH Bulletin"
Department of Mental Health
25 Staniford Street
Boston, Ma. 02114
Attn: Ann Madigan

Send us a fax at:
617-727-1538

E-Mail us at:
ann.madigan-DMH@state.ma.us

Children's Artwork to be Displayed at State House

The Parent Professional Advocacy League (PAL) will kick off Children's Mental Health Week with an art exhibit and reception from 5 p.m. to 7 p.m., Monday, May 5, at the State House.

The exhibit, entitled "Our Back Yard," will include more than 300 pieces of artwork by children and adolescents with emotional disturbance from across the state. The theme of the exhibit is "Communities: My Hopes, My Dreams, My Own Creation." It provides an opportunity for young people to display their creative talents. The reception will include guest speakers, honorees, friends and family, food and entertainment.

After the State House exhibit the artwork will be on display at various sites across the state. The first stop will be Boston City Hall from May 6-10. For more information on these events and others during Children's Mental Health Week contact Lisa Johnson or Pam Doherty at 1-800-537-0446.❑

CITIZEN MONITORING PILOT UNDER WAY IN METRO SUBURBAN AREA

The mission of the Residential Monitoring Program is to collect, record and report, through citizen involvement, client satisfaction with residential programs. This activity will contribute to the continuous quality improvement of those programs that are used by DMH's priority population.

Residential Monitoring Handbook: Client satisfaction with Residential Programs

By Connie Peters

The DMH Metro Suburban Area initiated a pilot program based on the work of the Statewide Advisory Council's (SAC) subcommittee on residential monitoring. After years of planning by SAC and its subcommittee, a Residential Monitoring Handbook was developed that focuses on obtaining information about client satisfaction. DMH staff presented the residential monitoring program to the Metro Suburban Area Board to gain its approval for the pilot project. Board member Eileen Murray is now serving as the residential monitoring coordinator.

A Metro Suburban Area-based planning group was established to plan the implementation of the pilot program, and volunteer monitors are being recruited through presentations to Alliance for the Mentally Ill affiliates, DMH clubhouses, and other community-based programs and organizations. Citizen monitors will receive training on how to conduct a monitoring visit and how to report on client satisfaction.

The citizen monitoring pilot program is applicable to all licensed residential programs operated or funded by DMH. These programs are licensed either by the DMH (adult) or by the Office for Children (child and adolescent) and include adult group homes and congregate living, Intensive Residential Treatment Programs (IRTPs) for adolescents, Clinically Intensive Residential Treatment (CIRT) programs, and Child/Adolescent Residential Services. All child and adolescent residential programs will be included in the monitoring process, regardless whether they are used as statewide resources or include beds funded by the Department of Social Services (DSS) or other youth serving agencies.

Those in DMH operated or funded residential programs or their parents/legal guardians will determine whether citizen monitoring visits may be conducted; whether monitoring visits will be announced or unannounced; whether monitors may visit individual rooms; the frequency of monitoring site visits; the time of day when monitoring visits may occur; and the length of monitoring visits.

The citizen monitoring pilot program conforms with the philosophy of a client-centered system of care. It focuses on deriving client satisfaction with residential programs through discussions with monitors who are sensitive to resident needs. It is the monitors' responsibility to educate residents on the value of their monitoring activities and to build relationships over time to improve the quality of residential programs.❑

Connie Peters is the Operations Director for Program Operations for the Department of Mental Health.

Two Research Centers of Excellence....

The Center for Psychosocial and Forensic Services at the University of Mass. Medical Center in Worcester and The Commonwealth Center at the Mass. Mental Health Center in Boston. The Department is funding these two centers for the purpose of bringing together some of the best minds and talent in Massachusetts to advance treatment and rehabilitation methods for chronic, persistent and severely psychiatrically ill patients. The Center at the University of Massachusetts Medical Center concentrates on Behavioral and Forensic Services. The Commonwealth Research Center focuses on Clinical Neuroscience and Neuropharmacology. Alan Green, M.D. and Jayendra K. Patel describe the medications available to treat Schizophrenia; Maryann Davis, Ph.D. reports on Project Nexus.

The New Pharmacology of Schizophrenia

by Alan L Green and Jayendra K. Patel

Schizophrenia, a disorder that afflicts 1% of the population, usually begins in adolescence or early adulthood. The symptoms include intermittent psychotic episodes (hallucinations, delusions, bizarre behavior) along with a lack of initiative, emotional unresponsiveness, social withdrawal and poor speech.

Since the early 1950s, the drug chlorpromazine (Thorazine) and its successors have revolutionized the treatment of schizophrenic patients by reducing positive (psychotic) symptoms and preventing their recurrence. Patients have been able to leave mental hospitals and live in community residential programs or their own homes. But these drugs are far from ideal. Between 20% and 30% of patients do not respond to them at all, and others eventually relapse. These medications are known as neuroleptics because they produce serious neurological side effects including rigidity and tremors in the arms and legs, muscle spasms, abnormal body movements, and akathisia (restless pacing and fidgeting). These side effects are so troublesome that many patients refuse to take the medications. Neuroleptics do not improve the so-called negative symptoms of schizophrenia (apathy, social withdrawal, inability to feel pleasure) and the side effects may even exacerbate these symptoms. Thus, despite the clear beneficial effects of the drugs, even some patients who have a good short-term response will ultimately deteriorate in overall functioning.

These deficiencies in the standard neuroleptics have stimulated a search for new treatments. Until recently, the search was limited by the assumption that any effective antipsychotic medication had to have the same mechanism of action as the traditional neuroleptics: blocking transmission by the neurotransmitter dopamine, and shutting down dopamine activity in a particular region of the brain. The situation changed in 1990 with the introduction of clozapine (Clozaril), a medication that became available in the late 1960s, but was later withdrawn from the market because of a serious side effect.

Clozapine was reintroduced because it became apparent that this medication has unique properties that differentiate it from the standard neuroleptics. It is effective for about one third of patients who do not respond to standard drugs. It seems to reduce negative as well as positive symptoms, or at least exacerbates negative symptoms less than do standard medications. Moreover, it has beneficial effects on overall functioning and may reduce the risk of suicide in schizophrenic patients. It does not produce the troubling neurological symptoms of the standard neuroleptics and, unlike those drugs, it does not raise blood levels of the hormone prolactin. (Excess prolactin may cause menstrual irregularities and infertility in women, impotence or breast enlargement in men.) Many patients who cannot tolerate stan-

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HELP for TROUBLED YOUTH

By Maryann Davis, Ph.D.

Becoming an adult is a demanding developmental time where adolescents are expected to complete their education, gain and maintain employment, reside outside the family home, become financially self supporting, develop adult friendships, and in some cases, begin their own families. For adolescents with significant mental health needs this stage is particularly difficult. Many older adolescents served by DMH lack the skills young people need to get through this transitional period.

Additionally, about half of the adolescents receiving DMH case management services end such services by age 19 because they do not qualify for adult continuing care. This leaves many youth with significant emotional and behavioral difficulties in facing the challenges of young adulthood without sufficient supports. Project Nexus is an experimental program that designs and coordinates services for youth between the ages of 17-23 with serious emotional or behavioral disorders who have received children's services in the public sector in the past. Over the course of three years, the project will serve 30 to 50 youth per year in Arlington, Belmont, Lexington, Waltham and Watertown.

The project has two components—an interdisciplinary case management team and a community advisory board. The Nexus transitional team is comprised of three individuals with expertise in mental health; vocational, independent living; and housing services. The team talks with professionals who have been involved with the youth and those who are likely to be involved in the future. It coordinates meetings of the adolescent, the family, and relevant professionals. They cooperatively design a service plan that addresses the young person's goals. The services and supports either exist in the community or are created using flexible funds. The team monitors services and initiates needed changes.

There are three major differences between the Nexus approach and traditional case management. 1) The transition team has flexible funds that allow it to bridge financial gaps that block entry into appropriate services. For example, the fund may be used to buy services that are not covered by insurance. The fund can also be used to promote independent living, such as helping with a security deposit on an apartment. 2) Each advocate serves up to 15 cases at a time which affords an opportunity to know each person in the program. 3) For most young people, this program will be the only case management services for which they will be eligible. Most will not be eligible for DMH case management once they reach age 19.

The Community Advisory Board includes individuals from child and adult human service agencies, and local school districts who may enact changes within their agencies. Membership also includes the business community and child and parent advocates. The board guides the transition team, reduces system barriers that the team identifies, and builds working relationships with the business community to provide employment, training and housing opportunities. It develops a plan where the responsibility for this population is accepted and financially supported by a public entity.

The outcomes of youth served in Project Nexus are being evaluated. They include education, employment, residential status, family and social functioning, substance abuse, corrections involvement, and clinical symptoms. The costs and benefits are also being evaluated.

Project Nexus is funded by a grant from the Van American Foundation. It is a collaborative project between the University of Massachusetts Medical Center, the Massachusetts Departments of Mental Health, Social Services, Mental Retardation, Public Health, the Rehabilitation Commission, and the special education programs of Arlington, Belmont, Lexington, Waltham, and Watertown.

Maryann Davis, Ph.D., is an Assistant Professor, Department of Psychiatry, Center for Psychosocial and Forensic Services Research, University of Massachusetts Medical Center and the Project Director and Principal Investigator of Project Nexus.

MASSACHUSETTS PRIDE IN PERFORMANCE RECOGNITION PROGRAM

For the past 12 years, state employees have been recognized at a special awards dinner honoring their exemplary performance in the work place. Last year's dinner took place Thursday, October 3, at the Sheraton Boston Hotel where Governor William Weld delivered the keynote address.

Fifteen Department of Mental Health employees and groups, including support, clinical and managerial staff, received Commonwealth Citations for Outstanding Performance. Some of the comments used by fellow employees to describe their work were "professional," "compassionate," and "creative." All contributed toward significant improvements in delivering services and in improving operations.

Among the DMH employees receiving this year's Pride in Performance Awards at the Sheraton Boston Hotel were: (from left, top) Sylvia Killion, Southeast Area; Joy Connell, Metro Boston; Utako Dwyer, Western Mass. Area; Tawny Hilton, Central Mass. Area; Marianne Callinan, Central Office; (from left, bottom) PRISM Coordinators, Medfield State Hospital, Metro Suburban Area, with Commissioner Marylou Sudders (Center); Hennessey 3B Staff Members, Westboro State Hospital, Metro Suburban Area.

STIGMA STILL the HURDLE... Panic disorder, easy to treat, not easy to diagnose. Typically includes: shortness of breath, sweating, tightness in the chest, dizziness..classic symptoms of a heart attack, but many times the correct diagnosis is panic attack. Some people would prefer to hear they were experiencing a heart attack than receive a psychiatric diagnosis. Panic attacks are not uncommon. Up to 10 percent of the population experience panic attacks at one time or another. **Why don't people get help?** Psychologist John R. Pelletier of Boston says, "fear that they will be labeled mentally ill keeps people away from professional help." There is help. At the **University of Massachusetts Medical Center,** the Behavioral Medicine Clinic runs group sessions concerning panic disorder. Call 508-856-5610. **U Mass outpatient psychiatry services** offers therapy and medication for anxiety treatment. Call 508-856-2551. **The Center for Anxiety and Related Disorders at Boston University** offers assessments and treatment. Call 617-353-9610.

COMMISSIONER SUDDERS ON STIGMA... "One task I would like to work on is fighting the discrimination and stigma experienced by people with mental illness. Unfortunately, such experiences are alive and thriving in our nation and in the Commonwealth. We saw it recently in the congressional debate on whether there should be mental health parity: there was the immediate cry that parity would be too expensive. Within our own state, there's a provision for indemnity insurance plans that you must offer at least a minimum of $500 for mental health coverage. Unfortunately, this provision is often used as the maximum, not the minimum. However, we do not have these same arbitrary ceilings for physical illnesses. Mental illness has been hidden in the closet for a long time and is not well understood by the general public. People don't understand unless mental illness touches a family member, friend or someone in their community. I am very committed to promoting increased understanding of mental illness. I want to work toward ending this discrimination, whether it occurs with insurance coverage, employment or housing. I know NASW (National Association of Social Workers) has worked actively on this issue. I urge the social work community and others who are committed to mental health to use their voices and join me in this effort."

(Excerpted from an interview with Leslie Donovan, LICSW, "Social Work Focus," newsletter of the Massachusetts Chapter of the National Association of Social Workers)

EVEN ASTRONAUTS and their FAMILIES FEAR STIGMA... The staff psychiatrist who is available to astronauts and their families is about as busy as the Maytag repairman, according to Skylab commander Gerald Carr who said he was unprepared for the psychological stresses of his 1973-74 record 84-day flight. "Nobody would go to him, Carr said. Neither husbands nor wives would admit they needed to see a psychiatrist, because they were afraid it would affect the possibility for a flight." NASA could go a long way in helping to eradicate this stigma with some basic education: that the brain is an organ of the body and should be treated as such.❑

Briefly Noted...

Managed Care Report... The Massachusetts Association for Mental Health, Inc., has published its first edition of *Managed Care Report*. "Our goal is to make the newsletter an important source of accurate and objective information about managed care," said Bernard Carey, Jr., executive director of MAMH. "We also hope the newsletter can become a vehicle or forum for the exchange of information about managed care — where it has been successful as well as where it needs improvement. We will strive to be straight forward and neutral. Our goal is to provide information and not advocate any particular perspective." The *Report* is free of charge and may be obtained by calling or writing to MAMH, 130 Bowdoin St., Suite 309, Boston, MA 02108, tel. 617-742-7452.

The film ***"Dialogues with Madwomen"*** is now available from the Public Affairs Office video library at Central Office. This 90-minute film was shown at the most recent DMH Human Rights Conference to about 650 mental health staff, clients, advocates and family members. It received a very enthusiastic response. Cathy Nash of the American Psychiatric Association describes the film as "poignant and moving, a candid documentary about women and mental illness." Anyone interested in borrowing the film should call Public Affairs at 617-727-5500, ext. 411 or 436.

Names in the News... The American Psychiatric Association has named **Steven M. Mirin, M.D.**, as its incoming director. Mirin is president and psychiatrist-in-chief at McLean Hospital and is also a professor of psychiatry at Harvard Medical School...The Massachusetts Alliance for the Mentally Ill has honored **Sheldon Bycoff**, founder and president of Vinfen Corp., as its Vendor of the Year. Vinfen is one of the largest human services providers in Massachusetts, serving more than 1,500 individuals.

Employment Connections II, a federally funded partnership program with the Department of Employment and Training, reaches out to people with mental illness who are jobless and homeless. Staff seek out prospective clients at homeless shelters, transitional residences, soup kitchens and inpatient units. They also welcome referrals from social workers. After clients are identified, the Department of Mental Health assesses their needs and helps to stabilize clinical problems. After a successful pilot program in Boston last year, Employment Connections was expanded to Lowell, Lynn, Quincy, Framingham, Worcester, Cape Cod and Springfield under a three-year, $2.17 million grant from the U.S. Department of Housing and Urban Development.

Mental Health Services: A Public Health Perspective, Bruce Lubotsky Levin, John Petrila, eds., Oxford Press, 1996. This book offers a comprehensive summary of a variety of community-based approaches with a discussion of core mental health services, including financial management, law, quality improvement and cultural concerns. The majority of the contributors are scholars from disciplines other than psychiatry. The book provides a framework to study mental health services within a public health context and includes an interesting discussion of the emergence of advocacy, consumer and family organizations and their influence on mental health services. ❑

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standard neuroleptics are able to take clozapine.

But clozapine has serious limitations. It was originally withdrawn from the market because it can cause agranulocytosis, a potentially lethal failure of the capacity to produce white blood cells. Agranulocytosis remains a threat that requires careful monitoring and periodic blood tests; with such monitoring, it occurs in less than 0.5% of patients taking the medication. Clozapine can also cause seizures and other disturbing side effects: drowsiness, lowered blood pressure, drooling, bed-wetting and weight gain. It is usually taken only by patients who do not respond to other drugs (although studies now under way are evaluating its potential for other patients as well).

Clozapine is not only more effective than standard neurolepties, but also differs in its action mechanism. Unlike the standard neuroleptics, it blocks D2 receptors only weakly. Instead, it enhances the release of dopamine in the prefrontal cortex, which governs planning and goal directed activity; this could explain why it sometimes seems to improve negative symptoms. Clozapine probably inhibits the release of dopamine in the mesolimbic area (and produces its antipsychotic effect) by releasing dopamine in the prefrontal region. The basis for clozapine's unusual mixture of actions is now being widely studied. It has a remarkably broad spectrum of neurotransmitter effects, acting at the dopamine receptors and at receptors for seratonin, norepinephrine, acetylcholine, and histamine. Many investigators believe that some combination of these actions perhaps, for example, the ratio of activity at serotonin and dopamine receptors is the key to clozapine's unusual clinical effects.

Researchers are pushing to develop new antipsychotic medications that have the virtues of clozapinc without its defects. One "post clozapine" drug has been available for a few years, a second has recently been introduced, a third may be introduced soon, and others are undergoing clinical tests. The first of these medications is resperidone (Risperdal.) Its ratio of scrotonin (5-HT2) to D2 receptor action is similar to that of clozapine. Early studies suggest that it is as effective as standard neuroleptic drugs for positive symptoms and may be somewhat more effective for negative symptoms. It produces more neurological side effects than clozapine but fewer than standard neuroleptics. Like standard medications and unlike clozapine, however, it raises prolactin levels. Risperidone is now prescribed for a range of psychotic patients, and many clinicians seem to use it before clozapine for patients who do not respond to standard drugs. They regard it as safer. More research is needed to determine whether resperidone is as effective as clozapine for these patients.

Olanzapine (Zyprexa), which has recently been approved by the U.S. Food and Drug Admistration (FDA), resembles clozapine pharmacologically. Clinical studies suggest that it is at least as effective as standard medications for positive symptoms and more effective for negative symptoms. It has fewer neurological side effects at ordinary clinical doses. and it does not significantly raise prolactin levels. Animal studies suggest that, like clozapine, it may increase the activity of dopamine in the prefrontal cortex. Although it does not produce many of clozapine's most troubling side effects, including agranulocytosis, some patients taking olanzapine may become sedated or dizzy, develop dry mouth, or gain weight. In rare cases liver function tests become transiently abnormal (fortunately without causing any serious harm up to this point).

Sertindole (Serlect), which is under review by the FDA, is another antipsychotic medication with some advantages over standard drugs in its effects on negative symptoms. Like clozapine, it has neurotransmitter effects at dopamine, serotonin, and norepinephrine receptors; unlike clozapinc, it has little effect at histamine and acetylcholine receptors. Clinically, it resembles clozapine in producing few neurological side effects and not significantly raising prolactin levels. Its most common side effects are nasal congestion, weight gain and, in men a reduced volume of ejaculation. Like some other psychiatric medications, it can cause changes in electrical conduction in the heart. The significance of these changes is unclear.

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A number of other new antipsychotic drugs are now being tested in hospitals and clinics throughout the world. In developing these drugs researchers have taken advantage of what we know about the unique effects of clozapine. Two of the new drugs , quetiapine (Seroquel) and ziprasidone, are in the later stages of testing and may be next in line for clinical use.

The introduction of olanzapine, sertindole, and other new drugs will dramatically expand the potential for treatment of patients with psychotic disorders. Neurological side effects will be of less concern, and the ability to treat negative symptoms could be an important advance. Information about the new drugs is still limited; we will not know how effective they are until they have been available for some time. Of the many questions that remain, a particularly important one is whether the drugs reduce cognitive deficits in schizophrenic patients, as some data on clozapine and risperidone suggest. Such reduction can lead to improved social and occupational functioning.

Meanwhile, researchers are learning more about when and how clozapine and the newer antipsychotic drugs should be used. Will the new drugs be as effective as clozapine for patients who do not respond to standard drugs? Should they be given to patients immediately or only when standard drugs fail? Will they be especially helpful for older people and children with psychotic disorders? Will they remain effective in the long run, over many years? Will they improve overall social and occupational function? Given what we now know about the unique action of clozapine and its successors, it is safe to say that a new era in the treatment of psychosis is upon us -- a change as important as the introduction of standard neuroleptics in the 1950s.❑

Alan Green, M.D., is Associate Professor of Psychiatry at Harvard Medical School. Jayendra K. Patel, M.D., is Medical Director of the Commonwealth Research and Evaluation Unit at the Massachusetts Mental Health Center in Boston, and instructor in psychiatry at the Harvard Medical School.

Recovery and Rehabilitation Conference

The Department of Mental Health, the Alliance for the Mentally Ill, and Choate Health Systems, Inc., are planning a recovery and rehabilitation conference for Friday, May 30, at Boston University's George Sherman Union. The conference, which will explore expectations and perceptions for recovery and rehabilitation for people with mental illness, is geared to psychiatrists, nurses, mental health workers, psychologists, quality assurance staff, social workers, human rights officers and other mental health professionals.

Keynote presentations will be made by Marianne Farkas, Director of Training and International Programs at Boston University's Center for Psychiatric Rehabilitation, Dr. Dan Fisher of the Eastern Middlesex Mental Health Center, and Dr. Ken Minkoff of Choate Health Systems.

The registration fee is $35. Call LeRoy Spaniol, Ph.D., at 617-353-3549 for more details.❑

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The DMH Bulletin

Massachusetts Department of Mental Health Vol.1 No 9 Summer 1997

From the Commissioner

Caring About Human Rights Falls to All of Us

By Marylou Sudders

The protection of human rights is the responsibility of each and every one of us. First and foremost is the vital role that citizens play in volunteering their time and energy to ensure that basic rights are protected.....on human rights committees, citizen boards, and a myriad of other groups.

Adults and children with mental illness share the same basic human needs and desires as others, and should share the same rights and responsibilities as every person across the country. For many of us, this is a given; but not for all. The Massachusetts Legislature is currently considering a bill outlining five fundamental rights for people with mental illness. Although there may be some scattered opposition, passage looks promising.

Senate bill no. 614 and House bill no. 2105 were recently reported out favorably by the Human Services and Elderly Affairs Committee. They ensure that the mentally ill have the right to be visited by families and friends; the right to access to legal advocates; the right to make telephone calls; the right to send and receive mail; and the right to privacy while dressing, bathing and using bathroom facilities.

As you know, the public mental health system in the Commonwealth is changing, with private and general hospitals playing an increasingly important role in providing acute or short-term inpatient services formerly provided by the Department. We must ensure that basic human rights protections that apply to DMH facilities apply to these private providers as well.

The Department, in conjunction with a coalition representing mental health professionals, clients, and legal advocates, drafted these two bills. They codify and clarify rights found in case law, state statute and agency regulations. They make these rights applicable throughout the mental health system, ensuring that all mentally ill people — regardless of where they receive inpatient psychiatric services — are treated with dignity and respect.

These rights do not cost a cent. They pay important dividends, however.

Since individuals with mental illness are viewed and valued first as people, our focus must be on the clinical needs of the individual, each with his or her own desires and needs. The Department of Mental Health, unlike other human service agencies, has dual responsibilities — patient care, as well as public safety — however. We take our public safety obligations seriously. DMH is committed to meeting these obligations in the most appropriate and publicly responsible fashion.

The Department provides individuals in our care with treatment and rehabilitation and provides it in the least restrictive environment, facilitating an individual's ability to live and succeed in the community. Planning and service delivery centers on the whole person and not exclusively on an individual's symptoms and illness. People with mental illness have the right to self-determination, to understand their symptoms and disabilities, to select the direction and means of their rehabilitation,

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their recovery ... their life.

People with mental illness deserve the same opportunities that all citizens have to live in a neighborhood, to receive an education, to develop a career, to find work that is meaningful, to enjoy social relationships and to fulfill valued roles in the community. Appreciating and building on a person's strengths supports rehabilitation and recovery and is paramount in the Commonwealth's public mental health system.

A primary issue is access into the mental health system in the least restrictive setting. As I stated in a letter to The Boston Globe, more extensive use of community services is the antidote for unnecessary hospitalization. The Globe's recent focus on involuntary commitment of people with mental illness goes directly to the issue of human rights.

It is the time and opportunity to sit down with all stakeholders to review the state's commitment laws. They have not been revisited since 1972.

The Department's proposed regulations, which are being reviewed, also take up the matter of human rights in a changing health care world. They increase DMH's oversight of the complaint process at private psychiatric hospitals. The Department is currently not involved in a substantial way beyond determining whether such hospitals have a complaint process in place for patients during a licensing review.

In addition, individuals with mental illness — like all citizens — should be free from discrimination and stigma. Unfortunately, they are not. Stigma is alive and thriving in our country and in our back yards.

For example, existing insurance coverage still treats mental illness very differently than physical illnesses. Why? Why is it okay to allow capricious and discriminatory insurance coverage for mental illness? Within our own state, HMOs and other insurers must offer a minimum of $500 coverage for mental health coverage. Why is it okay for the $500 to be the maximum?

Thirteen states have enacted parity legislation. We have an opportunity this year to gain mental health parity in Massachusetts. The Joint Committee on Insurance recently gave our parity bill a favorable report and sent it along to the Senate. If you have not yet written to your local senator or representative to endorse the regulation, please do so.

As I said at the outset, human rights is the responsibility of all of us. We have a primary duty to advocate on behalf of consumers; to educate and sensitize state and provider staff regarding human rights issues; and to serve as a resource. Many of the issues are complex. There are no easy answers, no quick fixes. Not one of us is always right.

It is important, however, that we take the knowledge from our individual perspectives and roles, channel our collective wisdom and experience into ending discrimination against people with mental illness and to ensure that human rights are protected. ❑

The DMH *Bulletin*

A quarterly publication of the Massachusetts Department of Mental Health, reporting state news and relevant information for clients and their families, mental health professionals, vendors of services, and all citizens interested in the goals and mission of this Human Service Agency.

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SPOTLIGHT on KIDS

By Jane Pafford

During Children's Mental Health Week in Massachusetts (May 4-10), the Parent Professional Advocacy League (PAL) and its parent coordinators sponsored numerous events to draw attention to the mental health needs of children. The league enlisted the support of the Department of Mental Health, child service organizations, corporations and individuals to raise awareness of these issues and of the stigma that burdens children and their families.

Studies show that at any given time, at least one in five young people experiences a behavioral, emotional and/or mental health problem. Five percent of all children and adolescents have disorders that severely disrupt their daily functioning. Of high school students in Massachusetts, 20% have said they had a plan to commit suicide, and 10% acknowledged attempting suicide in the past year. The public does not understand these disorders nor does it comprehend the complex needs of children as well as the emotional, social and financial impact their families experience.

PAL distributed more than 6,000 information packets statewide to legislators, libraries, schools, police stations, courts and service providers. In several towns, parents took packets to teachers, school board members and physicians. Many took posters to stores in their community.

The week was observed in many different and dynamic ways:

"A Night at the Wang III," an evening of multicultural song and dance featuring children and adolescents from DMH contracted residential programs in the Northeast Area, was presented at the Wang Center in Boston.

Express Yourself, an exhibition of art created by children and adolescents who are receiving services, was held at the Grand Staircase in the State House. Some of the scenery from "A Night at the Wang" provided a backdrop for the exhibition. Legislators honored included Senator Stanley Rosenberg, Rep. Paul Haley, Rep. Kevin Fitzgerald. Dana Lynn Koran received a prize for designing the Children's Mental Health Week logo and along with other children and their families, Dana participated in the reception and the art exhibit. Art exhibits were also organized by parents in Danvers and at the Fairfield Mall in Chicopee.

The Kathy Davis quilt, depicting her experiences and those of her family, was on display at the State House. It then traveled around the state accompanied by a video which is available for viewing. Contact Joan Norcross at 508-947-8779 extension 10.

Cindy Nicholls, PAL parent coordinator in the Chelmsford area, developed a videotape that explored signs children and adolescents display indicating the need for further evaluation. It also lists services available and how to get help. Parents, professionals and school personnel participated. The videotape aired on local cable TV and is available in English and Spanish. Contact Cindy at (508) 907-2732.

Educational programs were presented in the Chelmsford schools, Gateway Regional School District, and numerous other schools across the state. The Massachusetts School Psychologists Association distributed information packets and encouraged information sessions in the schools as they did last year.

Press packets were distributed to the media outlets state-wide. Several newspapers, including The Boston Globe, Somerville Journal, Chicopee Herald, Holyoke Sun and The Evening News in Salem, published articles, editorials and letters to the editor. NASW (National Association of Social Workers) also published an article in its newsletter.

Billboards depicting the logo were in place in Framingham, Plainville and Worcester. The billboards at North Station in Boston carried the message in-bound during morning rush hour and out-bound during evening rush hour. A banner also was flown in downtown Framingham.

Parents and service providers participated in radio and television programs from North Adams to Cape Cod to help the public understand more clearly the mental health needs of children and their families. On National Depression Screening Day, Channel 5 in Boston interviewed June Gross and her daughter, Viesa Novosielski, who told their stories describing the experience of childhood depression. June is the Director of PAL.

Funding was provided by the Department of Mental Health, PAL and numerous child service organizations, and parents. In addition to the funding provided by DMH, individuals and organizations donated more than $3,000. These funds provided the bags, mugs and the T-shirts that carried the Children's Mental Health Week logo.

Plans are under way to establish Children's Mental Health Week as a national event. PAL will continue to do its part in Massachusetts and in the national effort. For more information, call PAL at (800) 537-0446. ❑

Jane Pafford is Director of the Parent Professional Advocacy League (PAL) Support Network in Western Massachusetts.

Two Research Centers of Excellence....

The Center for Psychosocial and Forensic Services at the University of Mass. Medical Center in Worcester and The Commonwealth Center at the Mass. Mental Health Center in Boston. The Department is funding these two centers for the purpose of bringing together some of the best minds and talent in Massachusetts to advance treatment and rehabilitation methods for chronic, persistent and severely psychiatrically ill patients. The Center at the University of Massachusetts Medical Center concentrates on Behavioral and Forensic Services. The Commonwealth Research Center focuses on Clinical Neuroscience and Neuropharmacology. Dr. Paul Appelbaum presents a piece on violence and serious mental illness; Brina Caplan, Ph.D., Ed.D, Suzanna V. Zimmet, M.D., Anne Marie Magill, B.A., Sue Santos, M.S. discuss the first episode study at the Commonwealth Research Center.

Violence and Serious Mental Illness: A Review of the Literature

By Paul S. Appelbaum

The purpose of this account is to challenge what has been, for several decades, the common wisdom regarding the relationship between violence and mental disorder: that the mentally ill are no more likely to be violent than any other group of people.

Studies of discharged mentally ill patients in the U.S. (almost all from state hospitals) conducted from the 1920s to the mid-1960s showed they had a lower rate of arrests than the general population supporting the conclusion that the mentally ill were no more dangerous, and might even be less dangerous, than the remainder of the population.

Beginning in the mid-1960s, similar studies began to show that discharged mentally ill patients had a somewhat higher risk of subsequent arrest. However, this failed to change the common wisdom. It is noteworthy that the general public always resisted the conclusion that the mentally ill were no more likely to be violent than other people. This has always been chalked up to bias on their part.

The time has come to reexamine the relationship between violence and mental illness. New studies suggest that we were too sanguine in our hopes that the mentally ill would prove to be less violent than others in the general population. Research now suggests a clear link between some forms of mental disorder and a propensity for violence. Moreover, some intriguing research also points to a greater than expected ability on the part of mental health professionals to identify mentally ill persons who are at elevated risk of future violent behavior.

Studies fall into two categories: examination of rates of violence among the mentally disordered, and studies of rates of disorder among the violent. Examinations of violence among the mentally disordered can be divided into two additional categories. The first represents studies of violence among persons identified as mentally ill entered the mental health system. Lifetime rates of arrests for violent crimes are high when looking at rates of violence among mentally ill patients just before admission, and up to four months after discharge.

However, data from the MacAurthur Violence Risk Assessment Study make clear that not all groups of persons with mental illness manifest this higher risk of violence. Indeed, increased violence in analyses to date appears to be limited to persons who also have diagnoses of alcohol or drug abuse or dependence. Persons who only have diagnoses of major mental disorders show no greater rate of violence than a sample

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First-Time Patients Treated with the latest Antipsychotic Medications

By Brina Caplan, Suzanna V. Zimmet, Anne Marie Magill and Sue Santos

The onset of first-episode psychotic symptoms is a frightening and redefining event not only for a young person diagnosed with schizophrenia but also for a family. They feel they have "lost" a child, a brother or a sister.

Because schizophrenia is a life-long illness, even when a young person manages a rapid and relatively complete recovery from a first episode, the child is at some risk of becoming ill again. Not for all, but for many patients, schizophrenia is a relapsing illness: A first-episode patient who takes medication as prescribed, goes back to school or gets back to work, still may have a 50% chance of renewed psychosis over the succeeding two years.

Unfortunately, while helpful to many patients, the "typical" antipsychotic medications traditionally used to treat people early in the course of illness seem to have limited long-term effectiveness. With standard medications, many newly diagnosed individuals appear to experience a tolerance and then, within a relatively brief time, a reoccurrence of psychosis and the devastation of their hard-won social and personal gains. Moreover, current research on brain physiology suggests that each relapse may lay the ground work for the next outbreak of the illness, priming the brain to slip more easily into psychosis. In some patients, the pattern of temporary stability followed by relapse occurs repeatedly with each return to health taking place at a lower level of social and vocational functioning than the previous one. This forces the patient's quality of life into a downward spiral.

The Commonwealth Research Center is working to prevent a deteriorating course of schizophrenia and its resultant disability. Current research efforts center around the actions of new, atypical antipsychotic medication, including clozapine and clozapine-like compounds.

Previous studies by the staff at the center, led by Dr. Allan I. Green, along with the work of other researchers nationwide, have produced the hypothesis that clozapine's unusual actions in the brain may cause this medicine to be effective without the "tolerance effect" of standard antipsychotics. Possibly, other new, atypical antipsychotic drugs mimic clozapine in this respect.

Hypothetically, this means that a patient who takes clozapine before psychosis becomes chronic can lead a fuller, more independent life and spare a family some of the emotional and financial costs of long-term illness. More generally, if clozapine's effectiveness does not diminish over time, knowledge about the biochemical basis of the illness and its treatment has been increased. This brightens prospects for every young person diagnosed with schizophrenia.

Two studies of first-episode schizophrenia are now under way at the Massachusetts Mental Health Center in Boston. The first compares the effectiveness of clozapine to the standard medication haloperidol. The second compares the recently marketed medication olanzapine to halperidol. Together, these studies initiate a "First Episode Center" at the research center, where patients can be carefully assessed and treated while in the early stages of psychotic illness.

During the inpatient phase of both studies, patients stay in a 12-patient statewide psychiatric unit at Massachusetts Mental Health Center. Besides an opportunity to receive the latest in medication treatment, the unit offers an integrated program of individual, group, family, milieu therapy, and rehabilitation along with extensive community liaison services. The inpatient program focuses on current problems and pragmatic one-step-at-a-time solutions, such as securing housing and facilitating return to work or school.

Patients and families have deeper questions

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of the population drawn from similar neighborhoods. Researchers in this and similar studies, though, were only looking at hospitalized samples, raising the possibility that it is primarily mentally ill people who are likely to be violent who are hospitalized, and that the conclusions cannot be generalized to all persons with mental disorders.

To address this latter issue, it is appropriate to turn to studies of violence among mentally ill persons who are not selected by virtue of hospitalization. Two major studies indicate there is an increased risk of violence associated with community-diagnosed mental disorder that varies according to type of symptoms present. No symptoms elevate risk as much as alcohol abuse, but one symptom—delusions—interacts strikingly with alcohol abuse to raise the risk of violence. This is especially true for delusions of influence and control.

The second group of studies examines mental disorder among violent persons, divided similarly into two subcategories. The first looks at studies of disorder among persons incarcerated for violent behavior. These studies have found that the percentage of major disorders in jail and prison populations is several-fold greater than in the community. However, it could be that the mentally ill are selectively arrested (e.g., they are less able to flee after crime).

Therefore, we must also examine studies of mental disorder among violent persons arrested for their behavior. These large-scale surveys show as much increased incidence of mental illness among those who report violence, seeming to confirm the relationship between the two.

A final issue to be considered is the question of predictability of violence among the mentally ill. If the mental disorder is associated with violence, perhaps mental health professionals are more apt to predict it with a degree of certainy. One recent effort to examine this showed that patients predicted to be violent were significantly more likely to be violent than those not so categorized. Although mental health professionals were doing better than chance, prediction was not a highly accurate process. Still, the contention that they have no predictive accuracy appears to be untrue.

Where do we stand in our knowledge of the relationship between mental disorder and violence, and what are the implications? We appear no longer able to assert that there is no relationship between mental disorder and violence. How will this affect the mentally ill? Before we predict negative effects related to stereotyping all mentally ill people as violent, it might be wise to remember that the public at large never believed that there was no connection between mental illness and violence.

Moreover, although the studies cited suggest a casual relationship between violence and mental illness, the proportion to the variance is relatively small, nowhere near as large as the effects of age, gender, and education. And the proportion of violence accounted for by people with mental illness in our violent society is minuscule.

In addition, recognition of a link between mental illness and violence may have positive effects. To the extent that it encourages us to undertake further research to explore the causal mechanisms, we may learn a good deal more about mental illness and its impact on human functioning. To the extent that it provides an impetus to control symptomatology that appears to be the link between disorder and violence, it may encourage the funding of desperately needed outpatient and post-hospitalization services. And given that our society is more inclined to spend money on self-protection than on assisting the disadvantaged, this newly acknowledge link may provide motivation for channelling new resources into psychiatric research.

We have the obligation to talk about these results in a responsible manner, and to encourage the public to draw reasonable conclusions from them.❑

Dr. Paul S. Appelbaum, M.D., is Chairman, Department of Psychiatry, A.F. Zeleznik Professor of Psychiatry, and Director Law and Psychiatry Program, at the University of Massachusetts Medical Center.

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regarding the impact of the illness and its treatment. "What does it mean for my future, my work, my school?" "Will I be able to keep my old friendships and activities-how do I start new ones?" "How does stress effect my illness?" "Will I be able to date, to marry, or form a committed partnership?" "Could we as parents have prevented our child's illness?" "Will our child be gainfully employed, becomes self-supporting, be able to live independently?" "Can we avoid the arguments we've been having with our son or daughter?" "How can we explain schizophrenia to friends and relatives?" "How do we fight the stigma and the social isolation associated with schizophrenia?" Staff at the research center are committed to helping patients and relatives find the answers.

The center not only does research on new psychopharmacological treatments for schizophrenia, it also looks into the needs patients, families and links them with professional caretakers in the community. At this point, the center offers two-to-five years of follow-up research-related care to those who qualify as ongoing participants in first-episode studies, as well as consultation with their caregivers, and an ongoing family-support group.

Anyone interested in learning more about the center's studies of first-episode psychosis may call (617) 232-5274. ❑

Brina Caplan, Ph.D., Ed.D., a neuropsychologist at the Commonwealth Research Center, coordinates the NIMH sponsored first-episode study of clozapine versus haloperidol; Suzanna V. Zimmet, M.D., is the research psychiatrist at the First Episode Center and is responsible for outpatient treatment of all first-episode study patients; Anne Marie Magill, B.A., is the study coordinator and serves as Research Assistant for the clozapine vs. haloperidol first-episode study; Sue Santos, M.S., is the coordinator for the first episode olanzapine versus haloperidol study.

Actuarial Study Shows Minimal Impact of Parity On Insurance Claims

The actuarial firm of Coopers & Lybrand recently completed an analysis of the potential impact of mental health parity in Massachusetts. It shows that the effect of legislation now in the Senate is equal to 1.9% of current employer insurance claims or about $2.72 per member per month.

The expectation is that some employers will respond in various ways to at least partially offset any potential cost increases. With this in mind, the analysis expects employer contributions for health insurance will rise 0.76% or $1.09 per member per month. So, this is not a money issue; it is a fairness issue.

The mental health parity bill, recently reported out of the joint Committee on Insurance favorably, contains a compilation of the salient points in five separate bills and addresses the issues presented by 15 constituent groups collectively known as the Massachusetts Mental Health Coalition.

The Department has joined other coalition members in saying it is time for insurers to treat mental illness, a biologically-based disease, as they do any other medical illness. It is no longer okay to allow capricious an discriminatory caps on insurance coverage for mental illness.

More than 40 legislators support the bill that will align the Commonwealth with New Hampshire, Maine, Rhode Island, Vermont, Colorado, Maryland, Minnesota, North Carolina, South Carolina, Texas, Arizona, Arkansas and Indiana, which have approved mental health parity. Twenty seven other states, including Massachusetts, are currently debating the issue.❑

Most Americans are unaware of the warning signs of clinical depression; they consider it a "normal" life event. Findings from a 1996 survey of 1,166 adult Americans commissioned by the National Mental Health Association show:

Less than one-third of respondents are aware of the symptoms associated with clinical depression, such as anxiety, agitation and changes in eating and sleeping habits.

Nearly half believe depression is a normal part of aging. More than half would seek treatment from someone other than a health professional (friends, family, clergy.) One in four would "handle it themselves." Nearly one-third cite a lack of insurance as a barrier to treatment; 78% believe treatment should be fully covered.

More than half believe that depression is a sign of weakness, not an illness.

CONSUMER EXPERIENCE with STIGMA: RESULTS of a NATIONAL SURVEY, May, 1997

This study, the first to focus on the workplace experiences of individuals with serious mental illnesses, was released at the American Psychiatric Association annual meeting by the National Alliance for the Mentally Ill (NAMI.) Conducted by Otto F. Wahl, Ph.D., of George Mason University, "It confirmed our worst fears," said Laurie Flynn, NAMI Executive Director. "The stigma of severe mental illness prevents capable people from fulfilling their potential." Seven out of ten respondents said they have been treated as less competent by others when they revealed their illness. The survey shows that stigma is still prevalent in today's society:

I applied for employment at a well-known engineering firm and received a job offering with the condition that I bring a work release from my doctor. (The company knew that I had not been working due to illness.) When I gave them the note stating that I was mentally ill but could now work, they discovered they could no longer afford to hire me.

When I was first diagnosed, I made the mistake of telling my supervisor what was going on. She decided I couldn't do the job I'd had for ten years and demoted me.

Upon my return to work, telling my co-workers about my mental illness was not a consideration ... hiding it was. I didn't have the strength to defend myself against any prejudice they might have.

The study examined other areas (health care and personal relationships.) Findings include:

Approximately one in three consumers have had the experience of being turned down for health insurance because of their mental illness.

Half have often heard friends, co-workers and even mental health professionals make hurtful or offensive comments about mental illness.

More than one in five have been turned away because of their mental illness when they volunteered their services.

The results of this study underscore the importance of the Americans with Disability Act (ADA) guidance recently issued by the Equal Employment Opportunity Commission (EEOC). Stigma continues to exacerbate the many challenges people with mental illness must face, but identifying the stigma, as this study does, shines a light on this dark aspect of mental illness. ❑

Briefly Noted...

I'm Still Here: The Truth About Schizophrenia, is now available from the DMH video library. The film concerns Dan, a man in his 50s with a Ph.D. in calculus, who has been living with schizophrenia for 32 years; James, a musician who, after diagnosis and treatment, has resumed his career; a young female artist and animal lover who volunteers at a California zoo and a man who - after the film was shot - commits suicide. One of the medical consultants, along with Nancy Andreason, M.D., Ph.D., was Stephen Goldfinger, M.D., an assistant professor at Harvard Medical School. "There were already lots of educational videos, so the concept here was to do it through the eyes of the individual, to let people talk for themselves," said Goldfinger, who also chairs the American Psychiatric Association's committee on poverty and homelessness.

Obsessive Compulsive Disorders Institute has opened its doors in a house on the grounds of McLean Hospital in Belmont. With resources from the Massachusetts General Hospital, the program offers partial hospital and residential treatment for individuals with OCD (obsessive compulsive disorder), age 17 years and older. Michael Jenike, M.D., chairman of the OCD Foundation's Scientific Advisory Board and professor of psychiatry at Harvard Medical School says, "It is our hope that by combining seven-days-per-week behavior therapy and state of the art pharmacology, this facility will allow patients to get their normal lives back."

Employment Intervention ... While people with psychiatric disabilities are the second largest group of applicants for vocational rehabilitation, they have the lowest rate of success in the workplace. Even with high client motivation and family support, rates of employment for this population are low, ranging from 10% to 25%, according to Bernard Arons, M.D., director of the Center for Mental Health Services. To test the effectiveness of different employment interventions for adults with severe mental illness, CMHS began a collaborative, multisite Employment Intervention Demonstration Program. The Human Services Research Institute in Cambridge, is analyzing the data and costs associated with providing vocational rehabilitation services. "When dealing with the impact of mental illness in a person's life," Arons said, "employment intervention can provide a solid foundation for the road to recovery."

The Family Connection, a program run by North Essex Mental Health Center in Haverhill, is helping children and families, often enabling troubled families to stay together by offering new ways to succeed. Since the program began three years ago, some unusual and creative therapies have provided treatment for people who have gone the traditional routes and failed. Trips to the gym, karate, even horseback riding lessons, are turning young lives around. The $45-an-hour cost of riding lessons, paid for by the Department of Mental Health through this program, is paying big human dividends.

Time for scientists to talk back to politicians?..."When I was asked to walk the congressional halls for the Society for Neuroscience in an attempt to talk up more money for brain research, the staff people all said the same thing. In effect, 'It's a closed system: If you want more research money, you tell us which program to take money from. Don't think the money comes from making one less gun; it comes from the domestic budget. What is it you want to cut?" This was Michael S. Gazzaniga's experience at a recent symposium on drug abuse. Gazzaniga is the David T. McLaughlin Distinguished Professor and director of the Program in Neuroscience at Dartmouth College in Hanover, N.H. The government had recently announced that $1.5 million will be allocated to fund research on the role of cognition in addiction. "This is a silly amount," said Gazzaniga. "Just give us one billion of the drug control billions. It is time for scientists to talk back to the politicians. This is a no-brainer." ❑

Commissioner's Reception Highlights Distinguished Service

Marylou Sudders, Commissioner of the Department of Mental Health, presented 11 Distinguished Service Awards on Tuesday evening, May 13, to individuals, programs and organizations who have made significant contributions to people with mental illness in the areas of advocacy, education, research, treatment and rehabilitation.

The awards ceremony was held at the foot of the Grand Staircase at the State House. Light refreshments were served and music was provided by Brassworks, a musical group led by Bob Peterson, Director of Applied Information Technology, DMH Central Office.

Recipients in the seven award categories included:

Legislation

The Honorable Frederick E. Berry

Presented for ongoing work in creating an appropriate environment for the mentally ill in public housing set aside for the elderly and disabled and for support of proposals to expand services for emotionally disturbed children.

The Honorable Thomas Cahir

Presented for public support of clubhouse programs that have increased employment opportunities for adults with mental illness and for his strong backing of legislation calling for parity in mental health insurance benefits.

Trude Lawrence

Presented for support of legislation to develop the Boston State Hospital campus that ensures appropriate housing and employment for people with mental illness.

Massachusetts Mental Health Coalition

Presented for crafting, supporting and testifying on behalf of legislation ending insurance discrimination for mental illness.

Child/Adolescent Services

Deborah Janssens

Presented for exemplary leadership and creativity in establishing innovative, unique, dynamic approaches in treatment programs for children and adolescents with serious mental illness or severe emotional disturbance. After struggling with a long illness, Ms. Janssens died on May 23. She was 37.

Education

Kenneth Duckworth, M.D.

Presented for exemplary efforts to reduce the discrimination associated with mental illness by educating medical students and the public to understand the impact of stigma.

Research

Joanne Nicholson, Ph.D.

Presented for extensive research leading to improvements in parenting skills of mothers with mental illness who are at risk of abnormal psychosocial, emotional and cognitive development due to ineffective parenting, poor communication, and environmental concerns.

Rehabilitation & Recovery

Martin Koehler

Presented for inspirational personal experiences, leadership and advocacy through education, and lectures, writings, and projects that have helped other people with mental illness to break down barriers to recovery.

Adult Services

United Families, Inc.

Presented for an impressive array of programs for members, including a weekly social and learning session, a consumer-run gift shop, advocacy and visitation services to clients, counseling and support to families, and an informative newsletter.

Lilo McMillan Award

Winthrop and Judy Alden

Presented for a strong, unequivocal belief in the value of family support and advocacy and a commitment to ensuring that high quality, appropriate services are delivered to people with mental illness.

(top photo, from left): Senator Frederick Berry; Representative Thomas Cahir; Trude Lawrence; Deborah Janssens; (middle photo, from left) Kenneth Duckworth; Joanne Nicholson; Martin Koehler; Jean Allardice of United Families, Inc.; (bottom photo, from left) David and Frederick McMillan with Winthrop and Judy Alden; Massachusetts Mental Health Coalition members with Commissioner Marylou Sudders.

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The DMH Bulletin

Massachusetts Department of Mental Health Vol.1 No 10 Fall 1997

From the Commissioner

Suicide Prevention: A Call to Action in Boston

By Marylou Sudders

Amid an increasing number of troubling, tragic suicides of young people in South Boston, partnerships of city and state and public and private mental health agencies have taken shape to work on the problem. We are involved in the effort.

In March, I wrote to Mayor Menino, pledging DMH support in providing whatever assistance the city deemed helpful. The mayor's quick response in mustering the necessary resources to deal with this crisis speaks volumes for his concern.

Together, much has been done and the accomplishments have occurred without regard to who receives the credit. The clinical efforts to prevent additional suicides have been done quietly. Mental health clinicians are providing counseling and outpatient treatment. The collaboration highlights the work and successes to date, but clearly, it is not enough. Six kids have died by their own hand since the end of last year.

Many deeply committed individuals are helping South Boston youth and their families to understand that every problem has a solution and that life, which can be overwhelming, is precious and irreplaceable. Many have come to the table to pool resources and address the issue.

A successful collaboration with Boston Medical Center and the Behavioral Healthcare Network, a DMH service provider, has created an intensive, far-reaching, outpatient program that is delivering services from trauma intervention to assessment and treatment planning to service delivery in non-traditional, community settings. This unique program has recently been accepted by the Massachusetts Behavioral Health Partnership for those covered by Medicaid.

Robert Macy, the director of trauma intervention services at the Behavioral Healthcare Network of Massachusetts, completed a fact-finding study in the D Street housing projects where he looked at what might have occurred to prompt young people to take their own lives and to get a sense of the types of rumors and concerns shared by the kids in the neighborhood. He then met with staff and students at Boston High School, selected because many of the neighborhood teenagers are enrolled there.

Macy also worked to provide trauma intervention services at South Boston High School and talked with the staffs of high schools and community service agencies across the city to deal with rumors and information concerning suicide pacts, substance abuse and the like. In addition, Macy, working through Neighborhood Services, trained community center, Boston Housing Authority and South Boston Community Health Center. This is providing increased capacity during these obviously troubling times.

Turn to **(Suicide)** on Page 3

Inside This Issue:

PRISM: A DIFFERENT WAY OF SEEING

By Ann Madigan

When Betty Smith (not her real name) returned to Medfield State Hospital for the fifth time in the past 10 years, she informed the admitting doctor that she was back to stay. She had been asked to leave her state-staffed community residence because of her disruptive behavior. Betty did not plan to move again.

She knew Medfield and Medfield knew her, or so she thought. But Medfield State Hospital had changed since Betty had last been there. A program called PRISM was in place. It was designed to work in a new way with patients with serious and persistent mental illness who were in a state hospital.

PRISM stands for Psychiatric Rehabilitation Integrated Service Model, but its acronym more accurately describes what is happening at Medfield. PRISM is like cut glass, refracting light and color on lives and in places that had previously been dark.

David Starkey, Ph.D., Area Director of Clinical Services, met with Betty. They had worked together before and Betty knew Dr. Starkey as a friend and caregiver. After several regular sessions, things began to change for Betty. She became less angry, more self-sufficient and more goal oriented. What was going on?

Traditionally, long-term patients in state hospitals have been considered as not amenable to rehabilitation, that they were "too sick," that their illnesses required a care-taking environment, that empowering patients would create unsafe conditions for patients and staff.

The institutional heritage from the time when state hospitals had 2,000 patients instead of 200 is familiar and efficient. Doing something for an individual: helping with a shower, selecting clothes to wear or food to eat, making beds and doing laundry - takes less time and trouble than teaching a person to perform these tasks. Staff worried that PRISM was part of the public sector downsizing and some patients resisted the new freedoms and responsibilities. "Why should I do my own laundry? You've done it for the last 10 years. No. You get paid to do it, so keep doing it."

Roles, ideas and values had to change. Learning occurred on both sides. There were bumpy times, but PRISM worked by changing the nature of the hospital itself.

By the time Betty Smith arrived at Medfield, PRISM was ready for her. Dr. Starkey and a staff with very different expectations helped Betty express her needs and think about setting goals. It seemed that Betty wanted three things to happen in her life. She did want to return to her life in the community; she wanted to lose weight, and she wanted more contact with her mother. Furthermore, she was ready to do her part in this plan.

Betty started on a healthy diet. She began visiting her mother in the nursing home. She negotiated with the staff of her former residence for her return. Other patients, too, were making progress and reported an improved quality of life, higher levels of satisfaction with unit activities, and a dramatic improvement in their feeling of being involved in treatment.

It has been two years since Betty Smith left Medfield. Her self-confidence continues to grow and she is not planning a return to the hospital. Today, 95% of Medfield's patients participate in the PRISM program which has helped to establish a landscape that creates hope and supports recovery for the seriously mentally ill.

For more information, call David Starkey, Ph.D., Metro Suburban Area Office (508-359-732 ext. 4653, Massachusetts Department of Mental Health.

Ann Madigan is a member of the Public Affairs staff.

(Suicide) Cont'd from Page One

DMH and the Boston Medical Center have hired additional clinical staff as well for the South Boston Community Health Center. This is providing increased capacity during these obviously troubling times.

On the inpatient front, the Boston Emergency Services Team (B.E.S.T.) and Charles River Health Management, are collaborating to provide hospitalization for any child in South Boston who might require it, regardless of insurance. After a clinical assessment by B.E.S.T., Charles River Hospital, Bournewood in Brookline, Cambridge, and Westwood/Pembroke are being utilized. Charles River Health Management has also developed creative, flexible step-down and respite services as well at its Brighton-Marine campus. For example, as part of the effort, it has worked with suicidal youth, provided respite care and made it possible for families to stay with kids in crisis.

What is in place serves as a foundation to build upon, helping to devise treatment strategies and arrange for a rapid, simple process for teenagers and families in crisis. These efforts have made a difference. Kids with suicidal symptoms have been quickly hospitalized when necessary, trauma intervention has addressed rumors and concerns shared by teenagers in neighborhoods, and flexible, post hospital and diversionary services and respite care have played a key role in dealing with various types of crises.

The DMH *Bulletin*

A quarterly publication of the Massachusetts Department of Mental Health, reporting state news and relevant information for clients and their families, mental health professionals, vendors of services, and all citizens interested in the goals and mission of this Human Service Agency.

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NATIONAL DEPRESSION SCREENING DAY.....OCTOBER 9, 1997

National Depression Screening Day began in 1991 as part of Mental Illness Awareness Week. It has grown from 90 sites attracting 5,000 people to last year's 2,800 sites with 85,000 participating. In the last six years, it has drawn 350,000 people into screening sites. After this year's NDSD, there are plans to establish a year-round telephone number to help the public locate neighborhood screening centers. The event is sponsored by the American Psychiatric Association, Harvard Medical School department of psychiatry, American Association of Retired Persons (AARP), McLean Hospital, National Depressive and Manic-Depressive Association and the National Mental Health Association.

For a list of October 9 screening sites, call DMH Public Affairs (617) 727-5500 ext.436.

Two Research Centers of Excellence....

The Center for Psychosocial and Forensic Services at the University of Mass. Medical Center in Worcester and The Commonwealth Center at the Mass. Mental Health Center in Boston. The Department is funding these two centers for the purpose of bringing together some of the best minds and talent in Massachusetts to advance treatment and rehabilitation methods for chronic, persistent and severely psychiatrically ill patients. The center at the University of Massachusetts Medical Center concentrates on Behavioral and Forensic Services. The Commonwealth Research Center focuses on Clinical Neuroscience and Neuropharmacology. Joanne Nicholson, Ph.D., Alexis Henry, Sc.D., and Maria Marsh, M.A., at UMass present a piece on Projects for Parents with Mental Illness and their Family Members. Alan Green, M.D., Ann Cousins, M.S.N., C.S., and Julie Myer B.S., from the Commonwealth Research Center present a piece on new treatments for schizophrenia.

Projects for Parents with Mental Illness and their Family Members

By Joanne Nicholson, Ph.D., Alexis Henry, Sc.D., Maria Marsh, M.A.

Parents with psychiatric disabilities are an emerging group whose needs have been largely ignored by rehabilitation specialists and mental health service providers.

Existing parent education programs are often based on traditional clinical models developed for children at risk of child abuse, or models developed for parents without disabilities. Since such clients are not active participants in program development, existing services are often irrelevant to parents with psychiatric disabilities. They may even present barriers to parent's participation. There is no parent skills training model developed with systematic input from all stakeholders.

The following case example highlights many of the issues facing parents with mental illness:

- *A 22-year-old female college student was diagnosed as a substance abuser in remission, suffering from acute post-traumatic stress disorder and major depression. She became pregnant six months into remission, and six weeks after the death of her mother. Single and homeless her clinicians decided to have the newborn adopted, despite her family's objections. Clinicians did not consider any other options, according to the woman.*

- *Despite the fact that the woman had family support to keep the child while she attended college; and in addition to the fact that she remained sober and symptom-free during pregnancy; no parenting or housing issues were addressed. The child was subsequently adopted, and the mother became severely depressed. She was hospitalized for six months. No clinicians addressed her grief issues as a possible source of her depression during hospitalization.*

- *No one asked what would happen to this woman if she lost her child, or what would happen to the child if he loses his parent.*

The University of Massachusetts Medical School, Employment Options, Inc., a clubhouse model psychiatric rehabilitation program in Marlboro and the Department of Mental Health (DMH) have been working together for several years to describe the experiences of parents with psychiatric disabilities, identify their needs, and develop service initiatives. DMH, for example, currently funds a housing program for parents with mental illness and their children through Employment Options. Members and staff at Employment Options with the support of their Advisory Council, have expanded their efforts to develop the concept of "supported parenting."

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"Effective Research" and New Treatments for Schizophrenia

By Ann Cousins, M.S.N., C.S., Julie Myer, B.S., Alan Green, M.D.

Schizophrenia is a psychotic disorder, typically characterized by a number of symptoms, including, for example, hallucinations and thought disorders, but also affecting cognitive abilities and overall quality of life.

In the early 1950s, a group of "antipsychotic" medications became available for the treatment of schizophrenia. Although these medications— the "typical" antipsychotics — continue to provide great benefits, not all patients with schizophrenia respond well to them. For some patients, the side effects are an important problem; for others, relapse of symptoms can occur even with continued treatment.

A number of new medications —collectively known as "atypical antipsychotics"— have been developed that appear to have advantages over the "typical" antipsychotics. Clozapine, for example, appears to control positive and negative symptoms of schizophrenia better than the older agents in those patients who do not respond to "typical" medications. The post-clozapine agents, risperidone and olanzapine, also appear to have certain advantages, particularly in the treatment of so-called negative symptoms, such as loss of motivation.

The need for "effectiveness research"

As testing of these new drugs occur, it is becoming apparent that the value of the new agents may extend beyond their impact on symptoms. Traditionally, when a new medication is introduced into clinical practice, there already exits a series of 'efficacy" studies, suggesting that the drug has a particular impact on clinical symptoms when tested in tightly controlled settings, that minimize the effects of extraneous variables. While "efficacy" studies are required by the U.S. Food and Drug Administration before it approves a new medication for general use, such studies do not provide much information about how it will work in "real world" clinical settings.

"Effectiveness research" usually goes beyond the measurement of symptoms to assess such a "real world" impact of new medication. Clinical trials of new medications for schizophrenia that incorporate the principles of "effectiveness research" often involve assessment of the overall level of patient functioning and quality of life, neurocognitive functioning, family experience with the illness, consumer satisfaction, clinical service use and social costs of the illness and its treatment.

These broader "effectiveness" measures are important because the degree of symptomatology in a person with schizophrenia does not always predict their level of functioning. There are individuals who can work every day despite active symptoms; others have few apparent symptoms, but are unable to take care of needs. It is important to know what impact any medication, particularly a new type, has on the broader array of personal and social domains — beyond symptoms themselves. Improvements in psychotic symptomatology.

Assessments of "quality of life" attempt to measure social functioning and the overall level of consumer satisfaction. Since some aspects of the quality of life, such as individual satisfaction, are difficult to measure, researchers often use multiple types of rating instruments or scales to gather this type of data. While one scale, for example, may measure a person's subjective internal state, another provides complementary objective information about the person's external level of functioning.

Neurocognitive deficits may occur in many patients with schizophrenia. Thus, neurocognitive functioning is another important measure of medication effectiveness, and is a key indicator of the overall level of social functioning. While assessments of neurocognitive functioning have traditionally not been

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(**Nicholson**) Cont'd from Page 4

The newest initiative is the Parenting Options Project (POP), a three-year project funded by the National Institute on Disability and Rehabilitation Research, with additional support provided by DMH, Employment Options and the Center for Psychosocial and Forensic Services Research at the UMass. Medical School Department of Psychiatry. The goals of the Parenting Options Project are to develop an education and skills training curriculum for parents with mental illness and to develop a goal-setting and assessment tool for parents and their helping professionals. The first four curriculum modules to be developed will focus on: financial issues for parents with mental illness; legal and advocacy issues; communicating with your child about mental illness; and maintaining relationships with children in 'alternative' family situations, e.g., visitation issues, step-families, and the like.

Key to the project is the involvement of all stakeholders in identifying needs, developing and piloting curriculum and assessment materials, establishing parent groups, and evaluating the process.

Agency, clubhouse and community representatives participate on the Employment Options Family Project Advisory Council and the new POP Regional Clubhouse Consortium. Four research assistant transitional employment positions, established at the UMMS Center for Research, will create a pool of clients with program development and research skills for future projects. The first four research assistants, recruited from clubhouse sites, include Bruce Gillespie, Linda Gordon, Del Kimball and Maria Marsh.

The POP Project Coordinator, Jonathan Clayfield, may be reached at 603-856-5498 for further information about the Parenting Options Project.

Joanne Nicholson, Ph.D., is the principle investigator, Alexis Henry, Sc.D., is co-principle investigator and Maria Marsh, M.A., is a research assistant at the Center for Psychosocial and Forensic Services at the UMass Medical Center in Worcester.

(**Effective**) Cont'd From Page 5

included in trials of medication in the treatment of schizophrenia, newer studies, especially "effective studies", are beginning to do so.

The impact of any treatment on the people close to the patients —especially the family— is also clearly important. The term "family burden" has been used to describe the impact of illness in one family member on other family members. Newer medications that improve a patient's functional capacity and promote living outside a hospital may allow the family to be more involved in a patient's life. The family "kinship bond" may improve and worries about the individual may diminish. At the same time, however, family responsibility for patient care may increase. With that in mind, "effectiveness research" on new medications should assess overall "family burden" as one aspect of the "real world" impact of the new treatment.

In the current health care environment, cost is an essential ingredient assessment of treatment effectiveness. As a result, cost effectiveness studies have taken on added importance. In addition to the cost of the medication and the cost of clinical services, assessment of cost often includes "indirect costs," such as disability benefits, missed work opportunities and the financial burden on the family. Often, the cost of a new medication can be offset by other cost factors such as the decreased need for expensive inpatient hospitalization.

"Effectiveness research" study

The Commonwealth Research Center is currently involved in several "effectiveness" studies utilizing these broader domains. For example, studies of people within their first episode of psychosis employ many of these measures to assess long-term benefits provided by new medications. In addition, preliminary studies suggest that antipsychotic clozapine may improve aspects of cognitive functioning in patients with schizophrenia.

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One large "effectiveness" study, funded by the National Institute of Mental Health is currently under way at the Commonwealth Research Center. This study will ask whether clozapine or olanzapine is a better choice for patients who have some response to standard medications, but who do not do as well on them as they or their clinicians would like. The study assess changes in symptoms, quality of life, consumer satisfaction, family burden and neurocognitive functioning. It also will provide information about the social and economic costs of schizophrenia and its treatment. Given clozapine's important side effects, the study seeks to assess the comparative overall benefit provided by olanzapine for this population.

Other studies of the Commonwealth Research Center will be described in subsequent columns. Any reader interested in learning more about the effectiveness research program or other studies at the center please call 617-232-5274.

Julie Myer, B.S., serves as Commonwealth Research Center research assistant for the National Institute of Mental Health effectiveness study; Ann Cousins, M.S.N., C.S., a psychiatric nurse specialist at the Commonwealth Research Center, coordinates the institutes sponsored "Clozapine vs. olanzapine effectiveness study;" and Alan I. Green, M.D., is the principal investigator of the effectiveness study and the Director of the Commonwealth Research Center.

MENTAL ILLNESS AWARENESS WEEK

October 5-11, 1997

Kick Off Set For Mental Illness Awareness Campaign

A pioneering campaign to raise public awareness of mental illness and the effectiveness of proper treatment will be unveiled October 1 at the State House. Results of a public opinion survey concerning attitudes and perceptions of citizens regarding mental illness will be announced.

This first-of-its-kind statewide campaign of the Department of Mental Health (DMH) is designed to curb discrimination against people with mental illness. Discrimination will be eliminated by increasing public awareness and understanding that these biologically-based diseases interfere with normal brain function. Appropriate treatment, including medication, psychotherapy and supportive services, alleviates the symptoms of mental illness. Psychosocial rehabilitation services then help individuals to live productive lives in the community.

The market research, funded in part through a grant from Eli Lilly and Co., will help in developing a strategy to better inform the public about mental illness. The survey results will be used to help develop public service announcements promoting public awareness. Tipper Gore and Mike Wallace will serve as campaign spokespersons.

DMH Commissioner Marylou Sudders has formed a 35-member task force of opinion leaders from the administration, legislature, corporate and mental health communities and others to heighten public awareness of mental illness and to fight the stigma associated with it. Charles D. Baker, Secretary of Administration and Finance, and Danna Mauch, President of Magellan Public Solutions, are serving as co-chairs of the task force. The task force will help in increasing the public's awareness and understanding of mental illness.

In The News... In the New York Times Magazine Food column: "For Temporary Insanity Try A Bowl of Chilled Soup."

In the Boston Globe, on the opening of the Harbor Islands as part of the US park system: "For more than a century, the islands within Boston Harbor were considered suitable only for the likes of a psychiatric hospital, a prison and a garbage dump."

On the book cover of a new novel, "Love can overcome time, distance and the craziest of families. And crazy families are in ample supply. "Even the compassionate and world-famous physician of emergency medicine, the star of the 1987 book, *Emergency Doctor*, misuses the term, schizophrenia, when he complains, 'There is a schizophrenia to what this hospital is (Bellevue.)'

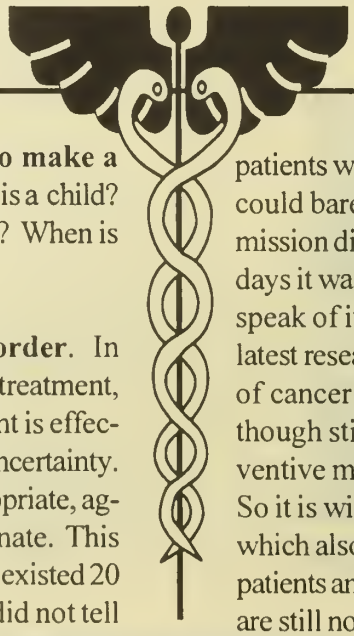
Along with "the evil genius and odd rapist, terrorist and drug baron," are other "freaks and monsters" being flown to a high-security prison designed to warehouse the worst of the worst." According to the movie reviewer of "Con Air" (The New Yorker (6/9/97) these guys will end up "doing raffia work, or whatever retired psychos do." And then, there was...

Schizo

..... a two inch headline in the New York Times, used to indicate "paradoxical."

NOTE: Schizophrenia is a brain disease that "strikes at the very core of what it means to be human. The combination of public misconceptions and ignorance along with intense internal suffering makes Schizophrenia perhaps the most tragic of human illnesses."

Nancy Andreason, M.D., Ph.D., Schizophrenia: From Mind To Molecule, 1994



Q. Why are physicians reluctant to make a diagnosis...particularly when the patient is a child? Why are they afraid to "label" a patient? When is a diagnosis a "label?"

A. When the illness is a brain disorder. In spite of the research showing that early treatment, even in some cases, preventive treatment is effective, patients often linger in a limbo of uncertainty. In no other illness would delaying appropriate, aggressive care be considered compassionate. This situation is analogous to the climate that existed 20 years ago with cancer. Doctors often did not tell patients what was wrong with them and the public could barely say the word cancer. Patients in remission did not tell employers or friends. In those days it was often a death sentence. Today, people speak of it openly, the newspapers report on the latest research, TV airs true and fictional accounts of cancer patients. The reason is that now, although still dreaded, cancer has treatments, preventive measures and even some apparent cures. So it is with mental illnesses, biological diseases which also now have treatments that offer hope to patients and families, yet because of stigma, people are still not "diagnosed, but "labeled."

Briefly Noted...

Phone Screening for Depression... The Employee Telephone Access Program designed to identify employees with untreated depression is in place at more than 100 companies with a total of 2 million employees. This anonymous, fully automated screening service is sponsored by the organizers of the annual National Depression Screening Day. Out of 31,000 calls in the past six months, 70 percent scored positive for depression. Callers complete a 10-question test, receive immediate results and are given referral information concerning their company's mental health services. Each company is assigned a toll-free number for employees and their families. Blue Cross and Blue Shield of Massachusetts became the first health plan to offer this service. Anonymous and confidential, the program reaches people at a stage when treatment is least costly and most effective. Advocates estimate that untreated depression costs American businesses about $24 billion a year in absenteeism and lost productivity.

Anti-Psychotic Drugs and HIV... Researchers at Johns Hopkins Children's Center found that Clozaril, an antipsychotic medication used by approximately 100,000 Americans to treat schizophrenia, inhibits the ability of HIV to replicate itself. Although Clozaril would have to be taken in such high doses that it would be toxic, the finding seems to add weight to the theory that schizophrenia may be partly viral in nature. "The fact that an antipsychotic drug can inhibit a virus, perhaps means that we can use antiviral compounds to help treat mental disorders," said Lorraine Jones-Brando, Ph.D.

S.O.S: Signs of Schizophrenia: What to Look For, What to Do... This is an educational program designed by the National Mental Health Association (NMHA) to increase public awareness of schizophrenia and make early detection and treatment possible. The brochure describes the warning signs of this "most debilitating and baffling of mental illnesses," contains facts and common myths about schizophrenia, its positive and negative symptoms, and includes a brief discussion on the importance of early treatment. For more information, call (800) 969-NMHA.

What Is It Like to Hallucinate? "Virtual Hallucinations," a simulated experience of schizophrenia, offered those at the recent American Psychiatric Association annual conference an entree into the frightening world of psychosis. Developed by Janssen Pharmaceutica and described as a "teaching tool to enhance understanding of schizophrenia," the exhibit invited visitors into a small enclosed room where they answered usual job interview questions: Where did you attend college? What is your work experience? What are your strengths/ weaknesses? Only these 'job applicants' were wearing earphones as they answered the questions. Strange voices, soft at first, but growing louder and more menacing, then laughing and accusing. Even knowing it was not authentic and would not last, participants could not muster enough concentration to complete a sentence. Perhaps others could learn from such an experience.

Former First Lady Rosalynn Carter is the Energizer bunny of human services. Always interested in issues of mental illness, she has authored a book based on her own personal and private experiences, *Helping Yourself Help Others: A Book for Caregivers.* Many people with mental illness live with their families who provide emotional, financial and social support. This is also true of families when a person with mental illness lives independently. Carter says that such caregivers must be helped before they become casualties themselves. "I hope physicians will refer people to psychiatrists for help without any sense of stigma or failure being implied. I hope the day has come that we can do that."

NAMI Family Education Program Receives DMH Support

By Lois Pulliam

"Journey of Hope," a family education program focusing on three major psychiatric illnesses, is in the midst of its third year thanks to funding from its local sponsor, the Alliance for the Mentally Ill of Massachusetts, and a significant assist from the Department of Mental Health.

The program was started in Vermont in the early 1990s by Joyce Burland, Ph.D., both a sibling and a parent of mentally ill women. **"Journey of Hope"** is an outgrowth of Burland's difficulties in dealing with professionals in the early stages of her daughter's illness. She received her doctorate before devising a way which family members could adapt to avoid the problems she and others encountered.

"Journey of Hope" is a 12-week educational program offered without charge to a maximum of 20 persons per session. Each participant must have a family member with a mental illness. Instructors, who have received intensive training, also must have a family member with mental illness and must commit to teaching the course at no fee for at least two 12-week sessions.

Topics include information concerning schizophrenia, depression and bipolar illness (manic depression); a detailed study of the brain; medication review; communication skills; rehabilitation; problem solving; crisis intervention; empathy; and advocacy that combats stigma and supports or opposes specific legislation. A useful by-product is the opportunity for family members to share concerns and successes, and to realize that consumers, families, the AMI, and mental health departments accomplish more as collaborators than as adversaries. In every state where **"Journey of Hope"** is taught — about 40 states to date — the curriculum includes up-to-date information about the legislature and laws relating to mental illness, the mission of the Alliance for the Mentally Ill and of the Department of Mental Health, the crisis services in place within each area, and information concerning drug policies. Those attending learn how to lobby effectively regarding budgets or other issues. Upon completing the 12-week course, graduates receive a certificate and an introduction to leaders/trained facilitators of a family support group.

The first **"Journey of Hope"** training in Massachusetts occurred in November 1994 with 16 participants who became teachers.

Typically, departments of mental health are strong supporters of **"Journey of Hope,"** with statistics showing that up to 75% of the states that offer the program receive DMH funding.

According to William Emmet, executive director of AMI of Rhode Island, "Educated family members make better, more informed, and more efficient use of services; educated family members help with treatment; educated family members make better advocates, and make AMI affiliates stronger and more diverse ..."

Graduates who were not in AMI before participating in **"Journey of Hope"** often join the Alliance during or shortly after the 12-week program. Some of these graduates also enroll in instructor training, which has meant rapid expansion in a short time span. There was additional training last year in Massachusetts — one session for facilitators only, the other for instructors and facilitators. A training weekend for instructors and facilitators was held this year. Five trainers in Massachusetts have participated in the national NAMI train-the-trainer weekend. Six members are on the **"Journey of Hope"** steering committee, including a person who was head of the program in Mississippi and moved to Massachusetts early this summer. This state now boasts six train-

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(Family) Cont'd From Previous Page

the-trainers, about 35 family instructors, and 32 facilitators for support groups. We are proud of the growth rate and appreciate the support of the AMI of Massachusetts and the funding from the Department of Mental Health that has made it possible.

Participants rave about the program. They show the depth of feeling of family members who have been literally starved for information concerning mental illness. By the end of the program, participants see each other as an extended family of empathetic adults who share problems and seek solutions. They have a new awareness and respect for the burden ill family members shoulder and for the frustrations of professionals who continue to seek, but may not find, answers to questions regarding these biologically-based brain disorders. They come away with fact-filled notebooks of information that serve as resources and bibliography material. Printing of the in-class and take-home materials —handouts for 20 people for 12 successive class sessions — represents a lot of paper. This has been one of the in-kind donations of DMH and it has been tremendously helpful.

As fall approaches, several 12-week programs are already scheduled, and more will undoubtedly be set up with fall and spring being the optimum periods,

Following is a listing of locations and contacts:

Charlie and Nancy Bacher will teach a course beginning next Spring on the Cape. Verify date, time and location with them at (508) 788-9167.

Ruth Denio and Sheila Wykes will be teaching a course in the Holden area starting September 4 and running through November 20. The location may be obtained by calling (508) 829-2940, or (508) 829-7763.

Win and Judy Alden are offering a course from 7 p.m. to 9:30 p.m. September 23 - December 16 at 333 East Street in Pittsfield. Until September 8, they can be reached at 1-902-963-3161 (Canada), and after that at their home in Williamstown at (413) 458-5887.

Greg Miller and June Robert will be teaching a course from 7 p.m. to 9:30 p.m. September 4 through November 20 in the president's dining room at the student center, F Building, upper level, at Northern Essex Community College in Haverhill. Call the Samaritans office (508) 688-0030, where they both work, to register.

There may be additional programs offered. Call Lois Pulliam (617)275-0090 for details.

Classes are limited to 20 registrants, and registration will be on a first-come, first served basis. Waiting lists are set up in the event of cancellations.

There are two more "Journey of Hope" curricula in the works — one for professionals and one for consumers — but there are no trained teachers on hand for either. Check periodically for updates.

Lois Pulliam, M.A., is Vice President of the Massachusetts Alliance for the Mentally Ill, Board of Directors.

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The DMH Bulletin

Massachusetts Department of Mental Health Vol.1 No 11 Winter 1998

From the Commissioner

Campaign Puts Focus on Changing Minds

By Marylou Sudders

A first-of-its-kind Massachusetts campaign to raise public awareness about mental illness and the effectiveness of proper treatment, treatment that should be noncoercive and voluntary, is under way. This is not my initiative; it is ours.

Individuals with mental illness, like all citizens, should be free from discrimination and stigma. Unfortunately, they are not. Increasing public awareness and understanding of illnesses that interfere with every day functioning and emphasizing the effectiveness of proper treatment puts the issue on the front burner.

As you know, mental illness affects individuals of all ages — children, adolescents, adults, the elderly — regardless of race, gender, income, religion, and education. One in every five Americans will experience an episode of mental illness in their lifetime. Approximately 5 million people, or 2.8% of adults, experience severe mental disorders yearly and 9% of children and adolescents between the ages of 9 and 17 are seriously emotionally disturbed.

In Massachusetts, this means:

- 600,000 adults have a diagnosable mental illness;
- 200,000 adults have a serious mental illness;
- 128,000 children and adolescents are seriously emotionally disturbed.

At any time in the Commonwealth, there are:

- 1,130 adults and kids in DMH inpatient settings;
- 5,929 in DMH residential programs;
- 7,000 in DMH-funded psychosocial clubhouse programs;
- 9,000 individuals who are DMH case managed;
- 18,000 in DMH community support services.

Severe mental illness defines a group of illnesses that causes changes in thinking, feeling and relating, resulting in diminished capacity for coping with the ordinary demands of life. While not enough is yet known to prevent or cure serious mental illness, treatment that generally combines medications with psychotherapy and supportive services can and does alleviate symptoms. These illnesses are treatable. Although severe mental disorders are long in duration, they can be effectively managed ... and, people do recover.

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Inside This Issue:

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Too often, we only see, hear or read about mental illness as it is perceived by Hollywood script writers, novelists, and the media. We seldom hear or read about the many people with mental illness whose treatment has allowed them to lead productive, meaningful lives in the community.

My hope is that the creation of a 35-member task force of opinion leaders from all walks of life will help to increase the public's awareness and understanding of mental illness and fight the stigma associated with it.

The results of a public opinion survey of Massachusetts residents, commissioned by the Department, once again confirms that misinformation is the principal reason why people do not see mental illnesses as a legitimate illness, in much the same way that they realize that arthritis, for example, is a disease of the bones and joints.

Paradoxically, a strong sense that mental illness is something to be ashamed of persists even though more than half of the people surveyed by Opinion Dynamics Corp. had personal experiences with mental illness. Some of those surveyed experienced an episode of mental illness while others had a member of their family, a friend or co-worker diagnosed as mentally ill.

Clearly, the survey's most dramatic finding was that, despite this personal encounter with mental illness, 90% of the public still believes that mental illness is so stigmatizing that most people avoid seeking treatment for as long as possible. Further, almost no one would let an employer know of the problem when he or she experiences symptoms of mental illness or is being treated for it.

This is not only tragic in terms of human suffering, but also in terms of public expense. Untreated mental illness will cost the nation an estimated $130 billion a year in lost income from jobs, as well as the additional societal expense of homelessness, associated drug and alcohol abuse, and premature death.

People with mental illness and family members need to know that treatment is available, that the illness can be managed, and that they can make significant contributions in society. If we can successfully heighten public awareness about mental illness, we can advance opportunities for individuals in the fields of housing, employment, education and access to health care.

I ask for your help in this endeavor. While I am delighted that Tipper Gore and Mike Wallace are serving as spokespersons for this statewide campaign, you will be able to do more in your community and beyond. Your help and support in this public awareness campaign is critical.

What can you do? Anything that you are comfortable with to raise awareness about mental illness and proper treatment ... from writing a short letter to the editor of your local newspaper the next time you see a story with an inappropriate slant to looking for a way to correct a myth in casual conversation with a friend. In our own way, we all can do something to combat the stigma associated with mental illness. Thanks for your help. ❑

The Stigma of Mental Illness: A Model Curriculum

By Ken Duckworth, M.D.

As a medical student, I was surprised that in four years of intensive schooling there never was discussion of a topic that had affected my family so much: the stigma of mental illness. I was troubled by this educational gap; from my family's experiences negotiating the medical field with my father mentally ill, I knew physicians should be more sophisticated in their understanding of the cultural stereotypes of people with serious mental illness. After I entered serious psychiatric training, I began to develop a curriculum for first and second year medical students who will treat people with mental illnesses, in clinics, surgery, and emergency rooms.

After eight years of teaching this curriculum to second year Harvard medical students, I received funding from the Massachusetts Department of Mental Health and the National Alliance for the Mentally Ill to develop a one-hour module on the stigma of mental illness for free distribution to medical educators.

The format of the curriculum includes a quiz, viewing a video, followed by discussion. The quiz is a six-minute survey of knowledge and attitudes about major mental illness. The facilitator collects the quizzes and starts the video, taking note of the most frequently missed questions, with an eye to including them in the discussion.

The video is 15 minutes long, professionally produced, and includes: 1. media copy, including cartoons, advertising, numerous film clips from children and adult films of stereotypical portrayals; 2. an organizational framework of stereotypes so students can recognize them in the future; 3. commentary by Kay Jamison, Lori Schiller, Mike Wallace, and others about the effects of stigma on their lives; 4. a rebuttal of these stereotypes; 5. brief modeling by myself, discussing the effect that stigma had on me as a child having a parent with bipolar illness; 6. a brief review of how the viewer can impact this important social problem.

Discussion follows with the focus on the students' response to the video and quiz, and their reflections on their personal experiences and fears about mental illnesses. Students often note other stereotypic portrayals on TV or comments by colleagues about "crazy people." Personal or family experiences may be related. The realization of how cultural stereotypes affect attitudes and care offers a powerful perspective for students. ❑

Dr. Duckworth is the Medical Director at Massachusetts Mental Health Center.

The DMH *Bulletin*

A quarterly publication of the Massachusetts Department of Mental Health, reporting state news and relevant information for clients and their families, mental health professionals, vendors of services, and all citizens interested in the goals and mission of this Human Service Agency.

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Two Research Centers of Excellence....

The Center for Psychosocial and Forensic Services at the University of Mass. Medical Center in Worcester and The Commonwealth Center at the Mass. Mental Health Center in Boston. The Department is funding these two centers for the purpose of bringing together some of the best minds and talent in Massachusetts to advance treatment and rehabilitation methods for chronic, persistent and severely psychiatrically ill patients. The center at the University of Massachusetts Medical Center concentrates on Behavioral and Forensic Services. The Commonwealth Research Center focuses on Clinical Neuroscience and Neuropharmacology. Charles Lidz, Ph.D., from UMass presents a piece on consumers' views of coerced admissions. Alan Green, M.D., Carla M. Canuso, M.D., Ellen S. Burgess, Ph.D., from the Commonwealth Research Center present a piece on schizophrenia and women's health.

Schizophrenia and Women's Health

By Carla M. Canuso, M.D., Ellen S. Burgess,Ph.D., Alan I Green M.D.

Schizophrenia is an illness that affects women and men equally, but its symptoms and consequences are often different in the two genders. Women with schizophrenia generally function better before they develop the symptoms, which come approximately five years later than in men. Women have more of the "positive" symptoms:

Hallucinations
Delusions
Mood changes

Men have more of the negative symptoms, such as emotional unresponsiveness and withdrawal, which are more persistent and disabling. Women tend to respond better to treatment, with lower relapse rates and a higher quality of life. They also require lower doses of antipsychotic medications.

These gender differences may be important in understanding schizophrenia and choice of treatments. The female hormone, estrogen, may help to explain some differences in symptoms and treatment response. For some women with the illness, estrogen may have a protective effect. Women's symptoms often worsen when their estrogen levels decline— for example— after the birth of a child, during a certain phase of the menstrual cycle, and after menopause. In fact, the superior response to treatment in women tends to diminish with age.

Estrogen's beneficial effects may be due to the way it acts on the brain and on the neurotransmitter dopamine, which functions improperly in the brains of people with schizophrenia. Another possible explanation for the more favorable response is that women accumulate higher levels of antipsychotic medication, and break them. This may also account for a woman's greater vulnerability to side effects, such as movement disorder.

The standard antipsychotic medications, such as haloperidol and chlorpromazine, at a slower rate raise levels of the hormone prolactin, which normally stimulates the production of breast milk. Elevated prolactin levels in women may cause disturbing side effects, such as glactorrhea (inappropriate breast milk release) and irregular menstrual cycles. When prolactin levels remain consistently high, estrogen levels may be reduced. Low estrogen

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Consumer Views of Coerced Admissions

By Charles W. Lidz, Ph.D.

Since before the advent of specialized mental health care, having a mental illness put a person at risk of coercive confinement. In spite of all of the progress in mental health treatments, the next millennium appears likely to begin with some people with mental illness still being treated against their will.

How do consumers' of mental health care experience such coercive actions? What makes them believe that an admission is coercive? Do the actions of family or friends play a role in the experience? What about police? What matter other than legal status?

These questions became the center of a research project conducted by the MacArthur Research Network on Mental Health and the Law. It has shed considerable light on these issues.

For many years, researchers and consumers groups have suggested that the law is not the only source of pressure on people with mental illness. Put another way, coercion and involuntary commitment are not the same. MacArthur researchers found there was a significant difference between coercion and involuntary commitment, but the nature of that difference was surprising. Although about 10% of the people admitted involuntarily reported that they had been coerced, nearly 35% of the involuntarily admitted consumers reported that they experienced little or no coercion.

To better understand the experiences of consumers, the MacArthur research group did intensive interviews with 157 people who were admitted to state and community hospitals in two different states. Consumers were asked to describe their experiences and their feelings about those experiences. The admission interviews showed that the feeling of being coerced or not had four other dimensions: feeling included, the motives of others, respect, and deceit.

Feeling included is sometimes paramount to consumers. Many of those interviewed reported they were angry, not because they were ordered to come into a hospital, but because no one attempted to persuade them that they should do so. One voluntary patient was angry with her counselor.

I said: 'You call yourself a counselor...Why did you decide to do this instead of...trying to listen to me and understand...what I was going through? And he said, 'Well, it doesn't matter, you know, you're going anyway'...I feel that if you are a qualified counselor you should be able to sit down and listen to your patients.'

Other people's motives in participating in the decision to admit the individual often played a crucial role in their assessment of their experience. Many consumers reported appreciating pressures from their family and clinicians to come to the hospital because they perceived them as caring about their welfare. Conversely, when they felt troubled, they were often angry if a relative or clinician did not take it seriously.

Interviewer: *How seriously did [family member] consider what you had to say?*

Consumer: "*she didn't really do any thing, she didn't take it seriously at all."*

Interviewer: *How about your sister?...*

Consumer: "*Oh, she must have been awfully serious, She must have cared be Cause she went and talked to the counselor.*

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increases the risk of osteoporosis, the bone thinning disorder that may lead to disabling fractures. The new antipsychotics, such as clozapine, olanzapine, and quetiapine, have little effect on prolactin levels, and may be less likely to contribute to the development of osteoporosis in women with schizophrenia.

Investigators at the Commonwealth Research Center are currently studying the effects of antipsychotic medications on sex hormones and the functioning of ovaries in women with schizophrenia. These studies may improve understanding of this devastating disorder and the ability to treat it. For more information regarding these studies, call the Commonwealth Research Center at (617) 232-5274. ❑

Carla M. Canuso, M.D., is a staff psychiatrist within the Commonwealth Research Center and instructor in psychiatry at Harvard Medical School; Ellen S. Burgess, Ph.D., is a staff psychologist at the Commonwealth Research Center and research associate at Harvard Medical School; and Alan I. Green, M.D., is director of the Commonwealth Research Center and assistant professor of psychiatry at Harvard Medical School.

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Much like Aretha Franklin's song, consumers repeatedly emphasized a need for respect: "I think that it should have been my decision. And I don't think...that they should have put an order on me like some sort of animal or something."

Finally, consumers reacted badly to deceit, no matter what the purpose. One mentally ill person described herself as angry at the hospital staff, not because they had committed her, but because they had distorted what she had said in the interview. This made her meet the commitment criteria as dangerous to others.

Although no one likes to be committed to a hospital against their will, clearly the way it is done is important to many consumers. ❑

Charles Lidz, Ph.D., is a research professor of psychiatry (sociology) at UMass Medical Center.

VOLUNTEER and STILL GET PAID?

Yes. The Commonwealth of Massachusetts makes it possible for its eligible employees to volunteer for up to the equivalent of of one work day per month, without loss of salary or benefits. For the past three years, the School Volunteer Program has sent hundreds of people into the schools to help in a variety of ways according to the needs of the school and the interests of the volunteer. Training is provided by the state in several locations. More information on this program is available from the Human Resources Division in each Area.

Since April, 1997, another volunteer option has been added, the Mentoring Program, an affiliate of the national One to One National Mentoring Partnership. The word, "mentor," comes from the story of Ulysseus, who, before he left on his long journey, asked a good and wise friend to watch over Telemarchus, Ulysses' young son. The friend's name was Mentor. By becoming a friend to a young person through an organization such as Big Brothers/Big Sisters, state employees are enjoying the rewarding experience of making a difference in young lives. For more information call Human Resources, 1 Ashburton Place, Boston, MA 02108 (617) 727-3777, ext. 392. ❑

Research Update: From The McLean Brain Bank

By Francine M. Benes, M.D., Ph.D.

For more than a 100 years, psychiatrists have wondered whether schizophrenia is a degenerative disorder. This idea developed from the common clinical observation that patients with schizophrenia often show a deterioration in their level of functioning in the first three to five years of illness. Emil Kraeplin, a famous neuropsychiatrist who worked in Germany during the late 1800s, saw this phenomenon in thousands of patients and coined the term, ***Dementia Praecox*** (Latin for ***premature dementia)*** to distinguish schizophrenia from the dementia seen in elderly individuals.

Kraeplin was convinced that schizophrenia was a degenerative disorder with a juvenile onset. He encouraged Dr. Alois Alzheimer to come to his institute to study this disorder. After examining many postmortem brains from patients with schizophrenia, he concluded there was no evidence of degenerative changes in patients with the illness. Despite this, many other investigators, who believed schizophrenia involved degeneration of the brain, went on to study postmortem brains from patients with this disorder.

In the first half of this century controversy followed. Remarkably, schizophrenia became the main focus of the First International Congress of Neuropathology in Rome in 1952.

The controversies over postmortem studies of schizophrenia in the early part of this century occurred because little was known about the brain and microscopic techniques were quite primitive.

In 1976, investigators began using brain imaging approaches to study schizophrenia. Using computerized axial- tomography (CT scanning), a highly reproducible finding of brain shrinkage was found in patients with this disorder. This change was thought to be consistent with Kraeplin's suggestion that degeneration might cause schizophrenia. But these studies were limited by the poor sensitivity of CT scanning and the inability to distinguish specific regions of the brain. Most patients with schizophrenia did not show such shrinkage.

More recently, studies of schizophrenia have benefitted greatly from a powerful new tool, magnetic resonance imaging (MRI). It has dramatically improved the ability to view the functioning human brain. In applying MRI to the study of schizophrenia, investigators have detected a subtle decrease in the size of certain parts of the brain believed to be important in schizophrenia. However, even with the marked improvement of image quality that MRI provided, it was impossible to pinpoint what might be responsible for the shrinkage observed in some patients with schizophrenia.

During this same period, postmortem studies of schizophrenia have provided critical information to implement brain imaging results. Several studies have provided definitive proof that patients with this disorder are not ill because of a typical degenerative process. When viewed under the microscope, it is almost impossible to distinguish the brain tissue of a schizophrenic from that of a normal individual. But then, how can we explain the fact that people with schizophrenia are usually very ill and have to take medication to stay out of the hospital?

The answer: sophisticated neuroscientific approaches are needed to see the differences in schizophrenia. Using such techniques, recent studies of postmortem brains that schizophrenia may involve subtle alterations in the way neurons talk to one another. Neurons communicate by using special molecules, called neurotransmitters. They are signaling agents released at nerve endings (synapses), which travel short distances and attach to

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March on Washington To Raise Awareness, Atttack Discrimination

"Walk the Walk"...For Lives Troubled by Mental Illness" will take place Saturday, May 9, 1998, in Washington, D.C. Its goal is to assemble at least 5,000 people and will include members of major mental health groups from the the nations capital and around the country. Marylou Sudders, Commissioner of the Department of Mental Health, is planning to participate. Organizers are patterning the event after similar walks held by AIDS and cancer groups, which have increased the level of awareness and understanding of these illnesses.

After reading a joke about the mentally ill in an article on the front page of the Washington Post, Dr. Bernard Arons, Director of the Center for Mental Health Services, looked for a way to attack such damaging stigmas and create a better understanding of mental illness. He commissioned Curtis Austin, director of the Office of External Liason for CMHS, to develop a project "to shake up awareness, to get people to think of something they don't think about normally." The idea of the walk resulted and support for it quickly grew.

Assisting with planning of the walk is the consulting firm of Hays, Domenici & Associates, headed by Nancy Domenici, wife of Senator Pete Domenici (R-N.M.) He co-authored last year's National mental health parity act. Patricia Kempthorne, a Hays, Domenici associate, expects that 1998 will be just the beginning, saying, "We look at this as an annual event."

For more information, call Kempthorne at 703- 714-2363.

Award Program Aims to Decrease Stigma in the Media

The first five recipients of the **Rosalynn Carter Fellowships in Mental Health Journalism** have each been awarded $10,000 to study specific mental health issues. This fellowship program represents a national effort to reduce stigma and discrimination against people with mental illness by rewarding accurate reporting and encouraging journalists to expand their knowledge of mental health issues. The William Randolph Hearst Foundation provides the funding for the awards.

"Journalists in all forms of media play an increasingly important role in shaping public understanding and debate about mental health issues," said John Gates, director of the Carter Center's Mental Health Program. "Activities, research, and projects completed through this program will help combat stereotypical language and images that perpetuate stigma and discrimination."

ConDUCKtors Apologize ...Management of Boston Duck Tours has apologized for derogatory and humorless remarks made by some of their drivers as the amphibious tour vehicles passed by the Department of Mental Health building on Staniford Street. In response to several complaints from people who had taken trips on the entertaining and informative "Duck Tour" of Boston and reports from employees who heard some of these remarks, Marilyn Berner, DMH Chief of Staff alerted company management. Duck's General Manager, Cindy Brown, responded promptly, graciously and generously, not only with an apology, but with an offer to staff and/or clients to schedule a tour! ❑

Briefly Noted...

HELP for STUTTERERS: Risperdal, one of the new antipsychotic medications, has been found in a recent study to reduce stuttering. Those taking the drug had, on average, a 48% improvement in their speech. The medication will undergo further testing before it is available for this treatment. Psychiatrist Gerald Maguire, M.D., wants people to know that stuttering is a brain disorder and that, although anxiety may make it worse, anxiety does not cause it.

ALTERING VISION CAN CHANGE EMOTIONS: Experimental goggles, taped over to allow vision only from the left or right lateral field, induced changes in anxiety and depression, according to a study of 70 patients at McLean Hospital. "A positive alleviation of symptoms is encouraging news," said Fredric Schiffer, M.D., the study's principal investigator, but an "added and perhaps more important benefit to wearing the goggles is that it can allow a person to better understand himself and his problems. I see the goggles not as a cure, but as a useful adjunct to psychotherapy."

EXPLORING ALL AVAILABLE TOOLS: With a budget of $2 million in 1991, Congress established the National Institutes of Health Office of Alternative Medicine. Funding has grown steadily, with $13 million proposed for 1998. Director Wayne Jonas, M.D., describes OAM's role to reexamine medicine and science in light of the unorthodox systems and concepts found outside conventional medicine, to "ask new questions" that have been "off limits and taboo. The goal of biomedical science is to provide us with tools to alleviate human suffering, and not to hold on with blind faith to dogma with a narrow world view."

ACCORDING to OAM DATA, more than half of the conventional physicians in the United States use or refer patients for alternative treatments. More than 80 percent of medical students in the nation would like more training in alternative medical practices. All of this would not surprise the father of American psychiatry, Benjamin Rush, M.D.,who wrote about herbal medications in his 1774 treatise, An Inquiry into the Natural History of Medicine Among the Indians of North America. A reminder from Dr. Jonas, however, that "the patients who use alternative medicine are not alternative patients."

RECOVERY, not STABILIZATION NOW THE GOAL: At the American Psychiatric Association recently in Chicago., Dr. David Pickar, Chief of the National Institute of Mental Health Intramural Program, and a highly respected neuroscientist recently stunned an audience of more than 2,000 clinicians when he said that "in five years, physicians who prescribe the old anti-psychotic medications instead of the new generation of cleaner, more effective drugs such as Clozaril, Olanzapine, Sertindole, and Risperdol would be subject to malpractice suits." ❑

Governor Signs Mental Health Bill of Rights

Governor Paul Cellucci has extended certain basic human rights for a broad population of individuals with mental illness by signing into law legislation guaranteeing them to patients admitted to private and general hospitals.

"I have signed legislation that guarantees basic rights for Massachusetts residents with mental illnesses. This law also will help erase many of the stigmas aimed at the mentally ill. All people deserve to be treated with respect, and not like second class citizens," said Governor Cellucci at the December 4 State House ceremony.

The bill, which received overwhelming support in both the House and the Senate, contains five fundamental rights:

The right to be visited by family and friends;
The right to access to legal advocates;
The right to make a telephone call;
The right to send and receive mail;
The right to privacy while dressing, and using bathroom facilities.

In a prepared statement, House Speaker Thomas Finneran said, "The law gives mental health patients the right to do things that you and I take for granted every day, such as picking up the phone, or enjoying personal privacy in their daily routines."

An amendment introduced by Sen. Therese Murray, co-chair of the committee on Human Services and Elderly Affairs, codifies new DMH regulations concerning reasonable access to an attorney, or legal advocate, physician, psychologist, clergy member or social worker. The regulations are effective Jan. 1, 1998.

The public mental health system in Massachusetts is changing, with private and general hospitals playing an increasing important role in the provision of acute or short-term inpatient services formerly provided by DMH. This legislation ensures that basic human rights protections that already apply to DMH facilities apply as well to private providers licensed by or contracting with the Department.

The Department, in conjunction with a coalition representing mental health professionals, clients, and legal advocates, drafted the legislation. "Through this law, private psychiatric hospitals will be on the same footing as their public mental health facility counterparts," said DMH Commissioner Marylou Sudders.

The rights outlined do not cost the Commonwealth a cent. They pay important dividends to people with severe and persistent mental illness. "There are still many people out there who think that the label of mental illness means people are incapable of acting on their own best interests, and that others should be making the decisions for us," said Judi Chamberlain a consumer /advocate who worked on drafting the bill.

The bill was signed after nine attempts failed. "After a number of years of similar bills not passing, the Department, together with a coalition representing clients, and legal advocates, worked on the legislation. I am grateful to the Governor for allowing the Department to have an active role in this bill and to the Legislature for making it a priority this session," concluded Sudders.❑

(**Bank**) Cont'd From Page 7

WHAT are the FACTS?

1. How many Americans will suffer with some form of mental illness?

a. One in 5,000
b. One in 500
c. One in 5

2. What percentage of the homeless have a mental illness?

a. 10 percent
b. 2 percent
c. 30 percent

3. How much do mental illnesses cost the nation each year?

a. More than $270,000
b. More than $270,000,000
c. More than $270,000,000,000

4. What percentage of all hospital beds in the United States are occuopied by people with mental illness?

a. 1 percent
b. 10 percent
c. 25 percent

5. If $1000 is spent on research for each muscular distrophy patient and approximately $11.00 is spent for research on tooth decay, how much is spent for each person with schizophrenia?

a. $130
b. $203
c. $14

If you answered "c" to all of the questions, you scored 100%.

other neurons using specialized molecules called receptors. Once a neurotransmitter has attached to a receptor on another neuron, it induces that cell to respond. Such sets of communicating neurons make up a neural circuit.

It is now widely believed that the communication process between neurons is not functioning properly in a person with schizophrenia. In order to learn more about this, laboratories are now trying to identify the precise ways in which neural circuits may be different in schizophrenia.

In some cases with individuals with schizophrenia vision and hearing are appropriate; yet, response to an ordinary question might be difficult to understand. We do not as yet know whether the proble in schizophrenia involves the actual wiring pattern of the brain (hardware), or the processing of information within its neural circuits (software).

To eventually gain a clear understanding of how individuals with schizophrenia process information and how this might differ in those who do not suffer with this illness, more postmortem brain research is critically needed. The study of the brain after death is currently the only means that we have for to obtain an answer . For more information about brain donation, call 1-800-BRAINBANK.❑

Dr. Benes, is Professor of Psychiatry (Neuroscience) at Harvard Medical School and Director of the Havard Brain Tissue Resource Center at McLean Hospital in Belmont.

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The DMH Bulletin

Massachusetts Department of Mental Health Vol.1 No. 12 Spring 1998

From the Commissioner

Legislature Advances Mental Health Parity Bill

By Marylou Sudders

A bill mandating full medical insurance coverage for mental illness has been moved for consideration in the House. Passage of mental health parity insurance legislation by the Senate in a 38-0 vote on April 2 marked the first time that such a bill had been acted on favorably in either branch. It is now before the House Ways and Means Committee.

The legislation, which went to the House as Senate bill 2165, calls for mental health benefits equal to benefits offered for medical illnesses in insurance plans. Sixteen other states, including all in New England except Massachusetts, provide mental health parity in insurance coverage. Twenty-six states, including Massachusetts, are debating the merits of treating mental illness in the same way as medical illnesses.

The bill that came out of the Senate provides a very strong anti-stigma statement. It puts the Commonwealth where it has always belonged — in the forefront of the health care field — and provides people with mental illness a level playing field when it comes to insurance coverage. The legislation orders insurers to treat adults with serious mental illness and children with serious emotional disturbances as they do others with physical illnesses. The $500 outpatient ceiling is gone; so are other artificially imposed caps on treatment of people with mental illness. High co-payments for treatments are also out.

The legislation covers inpatient, intermediate, and outpatient treatment in the least restrictive setting. It requires equal coverage for patients with alcohol or chemical dependency. The bill specifies that the person authorizing mental health services on behalf of an insurer be a licensed mental health clinician. The provision will mean more timely services for those in need.

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Parity Exemptions Put On Hold For Six Months

Key provisions of the federal parity law

- Insurance carriers must offer the same annual and lifetime payment limits for mental illness as they do for physical illness.
- Insurers may adjust co-payment deductibles, and the number of covered inpatient or outpatient visits as they see fit.
- Companies that demonstrate a 1% or greater cost increase due to parity may seek an exemption from the law.
- Applications must be made based on six months of actual claims data showing increased 1% or greater costs increases.
- Employers need only inform the govern ment that they are taking an exemption to the law; no prior approval is required.
- Insurers remain free to drop coverage for mental illness entirely.

Companies must prove that enhanced mental health benefits boosted costs.

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The legislation covers insurance companies, Blue Cross and Blue Shield, and health maintenance organization (HMO) plans offered in the Commonwealth.

The Senate vote came on the heels of unanimous approval by the Senate Ways and Means Committee. In moving the bill to the full Senate, Sen. Stanley Rosenberg, Ways and Means Chairman, said, "This legislation is designed to bring fairness and equity into an area of health care where a double standard has existed for far too long. With this bill, we can take a long overdue step in trying to help all people cope with the cost of necessary medical care and to remove the stigma often associated with it."

When and in what form legislation might emerge from the House is uncertain. But the joint Committee on Insurance, comprised of House and Senate members, overwhelmingly endorsed an earlier version of the bill late last year. An earlier version of the bill was heavily supported by the joint Committee on Insurance. Reps. Angelo Scaccia, Kevin Fitzgerald and Byron Rushing, all of Boston, are original sponsors of the legislation while Rep. Nancy Flavin, co-chair of the Insurance Committee, has been a vocal supporter of mental health parity.

Spokesmen for the Massachusetts Association of Health Maintenance Organizations are opposing the legislation, citing an amendment requiring that all mental disorders outlined in the American Psychiatric Association's Diagnostic and Statistical Manual be covered. They say this will require insurance coverage of conditions not currently, covered. But requiring coverage of a diagnosis according to accepted standards and requiring treatment to be medically necessary enables cost restraints for insurers.

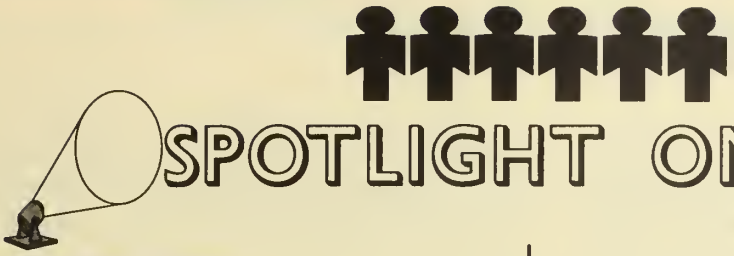
There is nothing in this bill that says insurers and HMOs can not manage the benefits. The Department is and has been the catastrophic insurer for those who have lost their insurance coverage or who have hit their lifetime caps. Society would not tolerate such discriminatory caps for cancer treatment or heart conditions, yet they have historically been allowed for mental illness.

As a Boston Globe editorial supporting the Senate action pointed out, "The bill acknowledges a reality that has finally gained public recognition ... that mental illness, like cancer, diabetes, and other diseases, is generally the consequence of a physiological disorder. Most insurance has always covered most of the costs of the other diseases while limiting protections against mental illness."

HMOs also state that the bill will substantially increase the cost of coverage. Facts have not supported predictions of enormous commercial premium rate increases. A Coopers & Lybrand actuarial study estimates the total impact of proposed Massachusetts mental health parity would be equal to 1.9% of current employer claims, or about $2.72 per member per month. The Senate bill would increase group insurance for state employees by an estimated $8.5 million a year, a 1.6% increase, according to the Senate Ways and Means Committee. A national UCLA/Rand study showed that removing the typical $25,000 limit on mental health benefits would raise group health insurance costs under managed care by only about $1 per enrollee per year.

A federal law, effective last January 1, was the first step in tackling these long-standing discriminatory insurance practices. This less-than-full-parity law requires insurance companies to offer the same level of coverage for mental illness as they do for other illnesses. It does specify that aggregate and annual payment limits be the same. For example, if an insurance plan has a $1 million lifetime spending limit for medical treatments, it cannot limit spending on mental health to $50,000.

However, the federal law falls well short of full parity because it does not require equality in inpatient days and outpatient treatment limits. It was a moral victory for those of us who advocate for the elimination of stigma for the mentally ill. The debate took the issue of parity and gave it national prominence. But I think we all acknowledge that there are significant weaknesses in the federal law. State laws are serving to plug the holes in the federal law, providing a two-pronged package to fight discrimination.



SPOTLIGHT ON KIDS

By Marion Freedman-Gurspan

Children's Mental Health Week will be celebrated May 4 through May 10. The purpose is to increase public understanding of child mental health problems and to demonstrate how these problems can be addressed when children, families, and the community work together. When families and mental health staff share expertise and planning for common goals, our young clients stand the best opportunity of receiving appropriate care. To help prepare the next generation of service providers, Commissioner Marylou Sudders and parents will be speaking at the graduate schools of social work on the theme of family collaboration.

Many conferences and events are scheduled across the Commonwealth during Children's Mental Health Week and throughout the month of May. Here are a few:

• April 30 - "**Innovations in Child and Adolescent Mental Health Services,**" Westboro Marriott Hotel, 5400 Computer Drive, Westboro, 8:30 a.m. to 4 p.m. The Honorable Martha Grace, the recently appointed Chief Justice of the Juvenile Courts, will be the luncheon speaker at this multifaceted conference for DMH staff, providers, and parents.

• May 9 - "**Beyond the Boundaries: Building on the Basics,**" Framingham State College, 9 a.m. to 5 p.m. The title for this year's annual conference of Family Ties reflects its cross-disabilities focus. The Southeastern Area's Parent Information Network (PIN) will represent children's mental health issues and services during the poster session. Kathy Davis, a PIN parent partner, will be a panelist discussing services and experiences from a parent's perspective, while Joan Mikula, DMH Assistant Commissioner for Child/Adolescent Services, will serve on a panel on government responsibilities.

• May 11 - "**Express Yourself: A Night at the Wang,**" Wang Center, Boston, 6:30 p.m. This fourth annual presentation of musical and artistic performances by children and adolescents from DMH residential programs is a joyous event for the performers and the many supporters who take delight in their achievements.

• May 12 - "**ADHD - What is it? What do we do about it? Physicians, parents and schools all working together,**" Nauset Middle School, Route 28, Orleans. Presenter, David S. Mishkin, Ph.D., Clinical Neurologist and Director of May Counseling Center.

• May 13 - "**School Phobia -A Psychiatric, Behavioral and Educational Point of View,**" Department of Environmental Protection, 20 Riverside Drive, Lakeville, MA 02347, 7 a.m. to 9 p.m. Speakers will be Alfred Darby, MD, Robert Sisson, Ph.D, and Marge Paccitti, M.Ed.

• May 20 - "**Greater Fall River Family Conference,**" Bristol Community College, 10 a.m. to noon. The conference will discuss programs, resources and services available to families of children with special needs. PIN will represent children's mental health services at a resource table during and after the event. Mary Gendron, PIN Director, will discuss PIN and children's mental health services in a panel discussion with other agency representatives.

• May 21 - "**Beyond Stickers and Stars-Functional Skills Training for Challenging Behavior Problems with Kids,**" Robert Sisson, Ph.D., presenter. This picture-tel conference will link all six Southeastern Area Parent Support Groups and other interested parents.

Each DMH Area has planned local events, and celebrations. On the evening of May 6, Commissioner Sudders will introduce Rosalyn Carter at the

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Two Research Centers of Excellence....

The Center for Psychosocial and Forensic Services at the University of Massachusetts Medical Center in Worcester and The Commonwealth Center at the Massachusetts Mental Health Center in Boston. The Department is funding these two centers for the purpose of bringing together some of the best minds and talent in Massachusetts to advance treatment and rehabilitation methods for chronic, persistent and severely psychiatrically ill patients. The center at the University of Massachusetts Medical Center concentrates on Behavioral and Forensic Services. The Commonwealth Research Center focuses on Clinical Neuroscience and Neuropharmacology. Dr. Paul Appelbaum presents a piece on the protections of research subjects. Larry J. Seidman, Ph.D., of the Commonwealth Research Center writes about new methods for testing the brain.

Neuropsychological Testing and Research

By Larry J. Seidman, Ph.D.

Neuropsychological testing, a way of examining the relationship between the brain and behavior, which was once used mainly by neurologists and surgeons, is being increasingly incorporated into psychiatric practice and research. These specialized procedures, often performed by psychologists, may help identify areas of brain damage and pinpoint particular cognitive deficits in higher functions, such as attention, memory, and information processing.

At one time, clinical psychologists determined brain damage mainly with Wechsler's intelligence tests, the Rorchach (ink blot) test, the Bender-Gestalt (visual-motor) test, and certain tests originally developed to assess personality. This traditional battery is still useful; for example, it can help in evaluating schizophrenic thought disorders, suicidal tendencies, hostility and in clarifying conflicts in male-female relationships. Traditional tests may also be useful for characterizing personality and cognition in complex disorders such as temporal lobe epilepsy and attention deficit hyperactivity disorder. But the results of these tests are not specific enough to identify such signs of brain damage, language deficits and attention problems. They do not provide the detailed information needed to plan treatment.

Today, the neuropsychological approach has replaced traditional tests for many purposes. Neuropsychological testing is appropriate whenever a patient has a diagnosis of possible brain dysfunction or when there is known brain damage and a need to evaluate the resulting strengths and weaknesses.

Neuropsychologists evaluate aspects of intelligence, reasoning, abstraction, attention, executive and self control functions (decision-making, planning, organization, and impulse control), learning, memory, language, auditory, visual, and motor functions, and constructional tasks (drawing a figure or assembling a design).

Neuropsychological tests resemble the mental status examination used by psychiatrists and neurologists, but the procedure is more elaborate and quantified, and the administration is standardized. The tests differ from neurological examinations by concentrating on higher cognitive functions rather than more elementary sensory and motor capacities.

A full battery of neuropsychological tests often takes three to eight hours to administer, but some patients can be adequately tested in an hour or two. Shorter forms of examination are becoming more common as more patients are referred to neuropsychologists for cognitive deficits - for

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Protecting Research Subjects

By Paul S. Appelbaum, M.D.

Are the subjects of psychiatric research afforded adequate protections? This question is raised in the media, in the courts, and by a number of state and federal commissions. Two factors seem to be driving this consideration.

First, doubts about whether protections are adequate to safeguard the interests of research subjects with mental illness have started to trouble family members of consumers involved in research. As recent articles written by some family members make clear, the perception that their relatives with mental illness are subjected to unfair and potentially harmful research practices, whether based on reality or not, evokes a sense of anger and betrayal. They are pushing for a broad examination of these issues. Not incidentally, were this perception to become widespread, one of the most potent voices for the importance of neurobiological research would be stilled, this at a time when new research techniques promise substantial insights into the pathophysiology of many forms of mental disorder.

Second, although it is impossible to gauge the nature and extent of problems in the conduct of psychiatric research from media coverage and a handful of court decisions, there are suggestions from other sources that difficulties may exist. The recently issued report of the Advisory Committee on Human Radiation Experiments (ACHRE), for example, includes results of a survey of selected human subjects' research funded by the federal government. Eight of the studies examined in the Committee's stratified sample of 125 projects involved cognitively impaired subjects, most with Alzheimer's disease. The ACHRE found that fully half of these projects, none of which offered direct benefits to subjects, had inadequate explanations of risks and discomforts in their consent material, and paid no attention to the question of how to deal with individuals who might have impaired capacities to consent to research participation. The latter finding confirms earlier indications that investigators frequently neglect issues related to subjects' competence. Combined, these factors have led to a reopening of formal discussion of the conduct of psychiatric research.

The current debate focuses on unresolved issues in three areas: methodology, informed consent, and institutional review board (IRB) oversight. Among the controversial issues in the methodologic area are designs that deny active medication to some or all subjects with conditions for which at least partially effective treatments exist. Concerns center on both the short-and-long-term consequences of relapse, especially in schizophrenia. Questions have been raised about the use of placebos in drug treatment trials, and there are related concerns about extended washout periods and discontinuation of medication in outpatients. Use of drugs that provoke symptoms, especially symptoms of psychosis, to tease out the mechanisms involved in psychiatric disorders, is another area of contention.

The most common rejoinder to concerns about placing research subjects at risk of harm -- for example, by use of placebos -- is that such practices are legitimized by the consent of subjects who agree to accept some possibility of adverse

Protecting the rights and well-being of individuals involved in research is imperative ...

outcomes for the sake of advancing knowledge. Since freely given informed consent is one of the ethical cornerstones of current research practices, it is troubling that some investigators' consent practices have been called into question. Projects have been criticized for failing to distinguish clearly between the benefits and risks to the individual of research and that of ordinary clinical care. Risks in general seem to be downplayed. Both problems may be exacerbated when researchers are also in charge of subjects' clinical treatment.

Practices regarding individuals with possible impairment of their decision-making capacities have also been questioned. The lack of clarity in our current system regarding the content of consent disclosures and how to recognize and deal with

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Schizophrenia Research Center

The Schizophrenia Research Center, located at the Freedom Trail Clinic of the Erich Lindemann Mental Health Center in Boston, is widely recognized by researchers in the field of schizophrenia.

The program was started 10 years ago when the National Institute of Mental Health (NIMH) selected Dr. Donald Goff as the recipient of a "Faculty Scholar Award" to study schizophrenia. Since then, the center has steadily grown, collaborating with the psychotic disorder program of Massachusetts General Hospital and as a component of the community mental health system managed by North Suffolk Mental Health Association.

The program serves as a training site for psychiatry residents from Massachusetts General Hospital, and offers training in nursing, psychology, and social work as well. The center's research and educational programs are funded by grants from the NIMH and the National Alliance for Research on Schizophrenia and Depression (NARSAD).

The center's goal is to develop clinical applications for new developments in the neurosciences. From the beginning, the center has tackled problems of great concern to individuals with serious mental illness and their families. This has included treatments for tardive dyskinesia (uncontrollable-body movements) and for psychotic and negative symptoms unresponsive to standard treatments. The researchers have pioneered the "glutamate model," demonstrating that D-cycloserine dramatically improves negative symptoms of schizophrenia and presenting evidence, in collaboration with Dr. Guochuan Tsai of the Massachusetts General Hospital, that glutamate neurotoxicity may play a role in the development of tradive dyskinesia.

More recently, center investigators have presented evidence which suggests that clozapine's unique efficacy for the treatment of negative symptoms may result from its glutamate activity. The center has received two NIMH grants to pursue research in this area. Dr. Eden Evins, supported by a

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FOCUS ON...

Re-search (re-sûrch) n. 1. Scholarly or scientific investigation or inquiry 2. Close or careful study (*American Heritage Dictionary*)

Yet research, particularly of the brain and central nervous system, means this definition and more. For people who suffer from mental illness, it offers the hope for better therapies and possible cures; for their families, it can mean the return of a loved one once lost to a world of hospitals, doctors and day programs; to scientists, it means the challenge and satisfaction of watching quiet miracles in an era of extraordinary discoveries about a machine more complicated than any ever invented -- the brain.

The participation of human subjects is an essential part of research. Without them, new medications for depression, psychotic disorders and other illnesses, to which the brain is vulnerable, could not become available to market. To protect subjects, Institutional Review Boards (IRBs) were established by the National Research Act of 1974. The act created the National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research. It mandated the commission to identify ethical principles relevant to human subjects research, to develop guidelines for conduct of such research and to examine mechanisms for review of applications to involve human subjects, particularly in cases involving vulnerable subjects, such as children, pregnant women, the mentally disabled, prisoners, and the economically or educationally disadvantaged.

Massachusetts, with its many medical schools, its high technology community, and its active and supportive mental health agency, is home to some of the most exciting research projects in the country. In this issue of the Bulletin (page 5), Dr. Paul Appelbaum reports on protecting research subjects. Future DMH Bulletins will explain the work of an IRB which meets once a month at Central Office under the direction of Fred Altaffer, Ph.D., and Mel Albert. J.D. Subsequent Bulletins will follow one proposal from the time the principal investigator presents the project to the board until, if and when, it gets under way.

PRIOR AUTHORIZATION--WHAT'S THAT?

Under "prior authorization," physicians must obtain permission from a third party, such as a managed care organization or insurer, before they can prescribe certain medications. In some health care plans, patients must first fail on older agents before trying newer and often more expensive therapies.

Restricting access may result in greater use of other health care resources, increased visits to doctors' offices or emergency room visits, and longer and more frequent hospitalizations. It may lead to increased tracking costs, including additional personnel, and expanded computer systems. Most important, patients may experience longer recovery times and diminished ability to return to the community.

The Massachusetts Department of Mental Health was in the forefront of the public sector when it made clozaril, the first atypical antipsychotic medication, available to its patients in the early 1990s. Since then, several newer antipsychotic medications have been introduced: Risperdal by Janssen, Zyprexa (Olanzapine) from Eli Lilly, Quetiapine (Seriquel) from Zeneca Pharmaceuticals. More are in testing phases.

These newer medications are approved as first line medications for people receiving services from the Department of Mental Health and the Massachusetts Behavioral Health Partnership.

In her testimony before the House Ways and Means Committee on March 3, 1998, DMH Commissioner Marylou Sudders said, "The Commonwealth has never placed caps on pharmacy services, allowing clinical needs of patients to determine costs. The costs of medications for the treatment of mental illness continue to escalate, in particular, the costs of the newer atypical drugs."

Since in some states, first time patients are routinely denied these newer drugs until they have failed on the standard, less expensive medications, the federal Health Care Agency (HCFA) recently notified all state Medicaid agencies of recent advances in the treatment of schizophrenia and called attention to the new antipsychotic medications. Included in the Medicaid alert was an analysis by the National Institute of Mental Health. Steven Hyman, M.D., Director of the Institute, pointed out that new SRI class of medications for depression have replaced the older and more problematic tricyclics and there is evidence that a similar shift in the "state of the science" needs to take place regarding the treatment of schizophrenia. Dr. Hyman also warns of the potential cost of lawsuits if patients are started or maintained on the older antipsychotics and at some point, develop tardive dyskenisia (uncontrolled movements.) "It would take only one or two lawsuits of this sort to make up the difference between the cost of generic, standard antipsychotic medications and the newer antipsychotics" which have a more benign side-effect profile.

"The Commonwealth has never placed caps on pharmacy services, allowing clinical needs of patients to determine costs."

Commissioner Marylou Sudders

"*Stabilizing schizophrenia patients with the new medications may seem costly at first, but it is a worthwhile investment...*" New England Journal of Medicine, 1996

ASHAMED? IT'S ALL IN YOUR HEAD ... Herbert Benson, M.D., Associate Professor of Medicine at Harvard Medical School and president and founder of the Mind/Body Medical Institute at the Deaconess Hospital, tells this "shameful" story in his recent book, *Timeless Healing*. A woman goes to a third doctor after many months of suffering from numbness and weakness that was severe one day and nonexistent the next. The symptoms were not confined to one area, traveling to different parts of the body. The first two doctors had told her, "It's all in your head," suggesting that she was not effectively managing the stresses of everyday life. The new doctor did a complete workup and extensive testing. At the end of the tests, she was told that she had multiple sclerosis, an incurable disease that can slowly destroy the nervous system, eventually causing death. But when the doctor told her this diagnosis, she responded, "Oh, I'm so relieved, I thought it was all in my head." Having symptoms deemed psychological is such a humiliating, stigmatizing experience in our society that the woman preferred to have a debilitating and life-threatening disease.

UNABOMBER CASE PUTS PSYCHIATRY ON TRIAL ... In an interview with Psychiatric Times, January, 1998, Thomas Gutheil, M.D., professor of psychiatry at Harvard Medical School and co-director of the program for psychiatry and the law at the Massachusetts Mental Health Center, said that keeping the media from trivializing or distorting what forensic psychiatrists say in court, is "hopeless." "Nothing overcomes deep running prejudice," Gutheil said. Theodore Kaczynski himself feared the stigma. "...They are bound to make me out a sickie," he wrote in his Journal. Dr. Gutheil noted that every time there is a high profile insanity case he goes on the air in Boston and "16 newspeople want to interview me about the insanity defense. We do it again, and we do it again, and it's the same problem every time. People simply will not accept it."

COMPETITORS! DROP DEAD! ... Qwest Communications International of Denver, a long-distance start-up company, has begun a series of TV commercials which depicts a young man named Bob perched on the top of a tall building, with a policeman trying to persuade him not to jump, until Bob mentions that he works for a long-distance phone company. "Then jump!" shouts the policeman. "You heard him!" screams a little girl nearby. The policeman rushes up to an onlooker and hollers, "Get up there and push that guy off the building!" The Wall Street Journal "raises questions of taste about 'Nasty-Funny Campaign.' (there are sequels to this horrific tale.)

The facts:

- **Officially, more than 30,000 people a year commit suicide. The actual number may be 3 to 5 times higher.**
- **More lives are lost to suicide than to homicide.**
- **On an average day, 84 Americans die from suicide and an estimated 1,900 adults attempt suicide.**
- **Over the course of a lifetime, be tween 20% and 40% of people with mental illness will atttempt suicide and between 9% and 13% will succeed in their attempt.**

MAY IS

MENTAL HEALTH MONTH

Briefly Noted...

University of Massachusetts to Build $12 Research Center ... On the grounds of Worcester State Hospital, groundbreaking ceremonies are scheduled for June 16 for a state-of-the-art neuropyschiatric research center. UMass Chancellor Dr. Aaron Lazare said the center will be one of only a handful of facilities in the nation devoted to biological research into the causes, diagnoses and treatment of chronic and serious mental illness. The university plans to recruit 7-10 major researchers in the field, and if successful, will reap $4-5 million in grants earmarked for projects conducted by those scientists. The state, through the Department of Mental Health, is providing $7.8 million. UMass expects to receive $3 million from an unnamed benefactor. Lazare said the center will focus only on research, although its work could have clinical applications for Worcester State Hospital patients. "We've always had an excellent relationship with DMH and by working that close to the state hospital, the researchers will be constantly reminded of the degree of suffering that the mentally ill endure," he added.

Research Links Obsessive Compulsive Disorder with Strep Infections ... There is an increasing body of evidence that indicates a relationship between childhood-onset OCD and certain previous streptococcal infections. Among children, the prevalence of OCD is 1 in 100. Beyond behavioral therapies and medication approaches to treatment, Susan Swedo, M.D., and Judith Rapoport, M.D., at the National Institue of Mental Health are studying possible connections between auto-immune illnesses and genetic markers for OCD that promise even more successful remedies for this disorder.

"Dead Blue: Personal Accounts of Depression"... DMH Central Office and Lindemann Mental Health Center staff had two opportunities to view this HBO film, featuring TV's "60 Minutes" Mike Wallace, author William Styron and psychologist Martha Manning, all of whom told their own disturbing experiences of serious depression and subsequent successful recovery. Those who saw the film found it entertaining and instructive. Dead Blue is available through the DMH video library. Call the Public Affairs Office, 617-727-5500 ext. 436.

Yale University Study on Voice -- Volunteers Sought ... Hallucinated voices are often reported by patients with schizophrenia and bipolar disorder. Researchers at Yale are now attempting to increase their understanding of this symptom by studying a treatment specifically targeting "voices." The study utilizes a procedure called transcranial magnetic stimulation or TMS. TMS delivers magnetic waves to certain, small parts of the brain. The strength of the waves is similar to those of an MRI scan and lasts from 10-15 minutes. Stimulation is administered while the patient is awake and it is not painful. Patients receive $300 for participating in the study, which takes place over a two-week period. During that time, patients stay at the Yale Psychiatric Institute for monitoring and assessment of symptoms. No changes in medication are made. For information, contact Ralph Hoffman, M.D. at Yale 203-785-3259.

ANOTHER BOSTON TEA PARTY

Dr. Robert F. Kenerson, a Boston-area psychiatrist, whose ancestor, David Kenerson, participated in the Boston Tea Party of 1773, joined approximately 200 other Massachusetts doctors and nurses to protest a "corporate, market-driven health care system that favors profits over compassion and clinical judgment."

> "corporate, market-driven health care system that favors profits over compassion and clinical judgment."

Gathered on the deck of the brigantine Beaver, they stepped up, one by one, to toss tea crates labeled Corporate Greed, Denied Services, Wasteful Bureaucracy, Rushed Hospital Stays, and No Care for the Uninsured. Dr. Kenerson hurled a wooden crate marked Loss of Confidentiality into the icy, winter waters of Boston Harbor.

Later that evening, at a town meeting in Faneuil Hall, Dr. Bernard Lown, winner of the Nobel Peace Prize and professor emeritus of the Harvard School of Public Health, reminded the audience, "When the original Boston Tea Party started (Dec. 16, 1773) nobody predicted a revolution. It happened."

Spreading Knowledge

The Department of Mental Health is distributing a three set educational video to all of its facilities to help spread the word on what mental illness is and how the disorder affects individuals and their familes.

The Bonnie tapes tell the story of Bonnie, a woman with schizophrenia, and how she and her family cope with this disease. Each tape explores a new subject, from mental illness in the family to recovery.

The Bonnie tapes are a valuable teaching tool for family members, clients, and mental health professionals. For more information, please call the Public Affairs Office at (617) 727-5500 ext. 436.

(Kids) con't from page 3

Odyssey Bookstore at Mt. Holyoke College in Hadley. Mrs. Carter will discuss her forthcoming book which touches on mental illness and families. There will be art exhibits at the Fairfield Mall in Chicopee, and at the libraries in Danvers and Lynn. Informative literature and brochures on services and programs will be displayed at many libraries across the state, and cable television shows and public service announcements are planned.

The celebrations are taking many forms. The Merrimack Valley Area is hosting a movie for families on May 2; and the Taunton/Attleboro Area will premier a Kids on the Block performance, targeted for the elementary school age population. Kids on the Block is an educational puppet program that promotes understanding of disabilities. This program will focus on children's emotional and mental health issues.

For up to date information, contact your local Area Office.

Marion Freedman-Gurspan is the Director of Special Projects for Child/Adolescent Services.

Mental Illness is a physical Illness.

Treatment works! Medication works!

Need Help? Get Help!

1-800-221-0053

The Department of Mental Health

The Alliance for the Mentally Ill of MA, Inc.

THIS MESSAGE IS ON THE GO

As part of her campaign, "Changing Minds: Raising Awareness About Mental Illness," DMH Commissioner Marylou Sudders has joined the National Alliance for the Mentally Ill of Massachusetts to promote the message, MENTAL ILLNESS is a PHYSICAL ILLNESS and MEDICATION WORKS.

Pat Lawrence, president of the state Alliance, initiated the advertising program by securing space on 18 billboards around the state. At the request of the Department, transit authorities in Worcester, Lowell, Greenfield, Merrimack Valley and Cape Ann agreed to carry this message as a transit card. More than 350 vehicles carried this message for a month as a public service, 200 of them on Massachusetts Bay Transportation Authority buses and trains. The so-called "car cards" display DMH's hotline number, 1-800-221-0053.

PATIENT "DUMPING"

Recent national headlines warn that mentally ill patients often get "dumped" from private hospitals by being transferred to public facilities. The implications for patients are dire, according to Robert A. Dowart, M.D. M.P.H., professor of psychiatry at Harvard Medical School and chief and chair of the Department of Psychiatry at Cambridge Hospital. One of the authors of the first national study of this type, Dr. Dowart said that "transfers disrupt the continuity of care and create a situation where patients are more likely to fall through the cracks of the treatment system."

During an interview on National Public Radio, he said, "In medical care, if you were to look at your own insurance policy, you would see there is some limit, but it's typically a dollar limit. For example, $1 million might be the maximum for your care in a given year. And so, if you have open heart surgery and have complications, you might be in for weeks of hospitalization. But you wouldn't reach your limit. And no one would say, 'your time is up, you're not better, but you'll have to leave and go home.' It would be unthinkable."

The authors of the study urged policymakers to improve health care access for the uninsured and the underinsured, cautioning that the current position in some states could only worsen the plight of the mentally ill.

(ARCHE) con't from page 5

patients with impaired capacities magnifies these problems, leaving even well-meaning researchers at risk of post hoc criticism. Surrogate decision making and advance directives, widely discussed as mechanisms for addressing some of the problems related to incompetence, are infrequently used because of continuing uncertainty regarding the legitimate scope of their application. Subjects and researchers alike would benefit from classification of these issues.

Finally, the role of IRBs in overseeing psychiatric research -- and perhaps research in general -- has evoked dissatisfaction from all parties involved. It is commonplace by now to bemoan IRBs' excessive and nearly exclusive focus on the content of consent forms as their primary mechanism for protecting subjects' interests. Given that existing regulations grant IRBs substantial discretion to devise other means to achieve this goal, their reluctance to do so is somewhat puzzling. Perhaps it stems from IRBs members' unfamiliarity with psychiatric disorders and the particular problems they present in research settings. Whatever the cause, discussion of ways to improve IRB performance seems amply justified.

Perhaps it stems from IRBs members' unfamiliarity with psychiatric disorders and the particular problems they present in the research settings.

Taking the Next Steps

How can we begin to address these issues in a responsible manner? Finding an answer to this question is critical, because of the delicate balance of interests involved. Protecting the rights and well-being of individuals involved in research is imperative, but so too is advancing knowledge of the causes of and treatments for psychiatric disorders. Even if public attention fades, the issues will remain. We ought to take advantage of the moment to develop a reasonable mechanism for tackling these dilemmas.

The National Bioethics Advisory Commission is about to issue a report on research with cognitively impaired subjects, which may have some helpful suggestions. But the Commission's effort, no matter how thoughtful, is unlikely to put these matters to rest. At a minimum, there will be considerable debate about the extent to which their proposals should precipitate a reformulation of the governing federal regulations on research. Even in the absence of new regulations, however, there is much that IRBs can do now to improve the situation. The list of possible approaches is a long one. It includes: asking investigators to specify how they intend to deal with subjects whose capacities may be impaired; how such subjects will be identified and evaluated; devising informational procedures that will help subjects with marginal capacities to attain adequate understanding; developing mechanisms for insuring that subjects enrolled in studies understand and appreciate the situation they are entering; justifying the use of placebos and medication withdrawal, and providing appropriate protections for subjects who are undergoing such procedures.

Other questions will be more complicated to resolve. Under what circumstances does a surrogate decision maker give consent for an incompetent subject to enter a research project, and who that surrogate should be?

The temptation for those involved in psychiatric research to see questions concerning practices as troublesome impediments to advancing knowledge should be resisted. Equally important societal interest in fairness and protection of the vulnerable are at stake. The time is right to push for a consensus on these issues.

Dr. Paul S. Appelbaum, M.D.. is Chairman, Department of Psychiatry, A.F. Zeleznik Professor of Psychiatry, and Director Law and Psychiatry Program, at the University of Massachusetts Medical Center.

(TEST) con't from page 4

example, elderly people with possible dementia and young adults who fear they may have attention deficit disorder.

Changes in mental state occur in many disorders, including schizophrenia, bipolar illness, alcoholism, brain tumors, kidney disease, and diabetes, or as a result of medication, surgery, or other medical procedures. Therefore, repeated neuropsychological testing may be useful in clarifying the progress of a disorder, evaluating the results of treatment, or comparing a patient's subjective symptoms with objective test measures. For example, the standard antipsychotic medications given to chronic schizophrenic patients are known to have only a minimal effect on most neuropsychological tests at the usual doses, although they do tend to improve some forms of attention dysfunction. However, many residual deficits remain and researchers are searching for new treatments that may ameliorate neuropsychological dysfunctions as well as positive psychotic symptoms.

These specialized procedures, often performed by psychologists, may help identify areas of brain damage and pinpoint particular cognitive deficits in higher functions, such as attention, memory, and information processing.

The newer, "atypical" antipsychotics, such as clozapine and risperidone, appear to relieve some of the neuropsychological symptoms of the disorder. The Commonwealth Research Center has demonstrated improvement in memory functions in schizophrenic patients, even in those with chronic schizophrenic illness, in patients treated with clozapine. Studies in other centers have noted that the post-clozapine drug risperidone may also improve aspects of cognitive functioning. These encouraging findings, which are being tested in other studies and with the entire array of novel antipsychotic drugs, provide new hope for those patients with schizophrenia whose social functioning is impaired because of neurocognitive disability.

Larry J. Seidman, Ph.D., is Director of the Neuropsychology Laboratory at the Massachusetts Mental Health Center, a research psychologist at the Commonwealth Research Center, and Associate Professor of Psychology in the Department of Psychiatry at Harvard Medical School.

Walk The Walk

for lives touched by mental illness

Saturday May 2, 1998

Freedom Plaza
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Mental Health Adviser to the President
Donna Shalala
U.S. Secretary of Health and Human Services
Rosalynn Carter
Chair, Carter Center Mental Health Task Force

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con't from (STUDY) on page 6

NARSAD award, is also conducting studies in the field.

Cognitive impairments remain one of the most troublesome and least treatment-responsive aspects of schizophrenia. The Schizophrenia Research Center is one of only two locations in the country studying a new medication, ampakine, that has shown considerable promise in animal studies as a cognitive enhancer. Ampakine is being developed to combat schizophrenia and Alzheimer's disease. The glutmatergic drug, D-cycloserine, demonstrated improvement in memory in a preliminary study in patients with schizophrenia and is being further tested at the center for its cognitive effects.

the center has tackled problems of great concern to individuals with serious mental illness

In collaboration with Dr. Ileana Berman of Taunton State Hospital, and funding by a NARSAD grant, the Schizophrenia Research Center is also conducting a trial of ginkgo biloba for cognitive deficits in patients with schizophrenia.

One of the most exciting new directions in psychiatric research is Repetitive Transcranial Magnetic Stimulation (rTMS), a technique that uses a magnetic coil placed on the scalp to selectively activate specific areas of the brain. The center is working with Dr. Alvaro Pascual-Leone, a leader in the development of rTMS, to explore its use as a therapeutic approach for individuals with schizophrenia who fail pharmacological treatments. Along with Drs. Robert Birnbuam and Dara Manoach, researchers are also using rTMS to examine brain function in patients with schizophrenia and the effects of antipsychotic medication.

The center is also applying the latest development in neuroimaging to look at brain functioning. The centers research team is working with Drs. Scott Rauch, Stephan Heckers and Dara Manoach at the Neuroimaging Center at Massachusetts General Hospital, and Drs. Perry Renshaw and Debbye Yurgelun-Todd at the Neuroimaging Center at McLean Hospital. These collaborations are funded by three NARSAD grants. By introducing new approaches to activating and measuring brain function, this work has produced several important findings that contribute to understanding of brain function in people with schizophrenia.

Another major focus of the center is the study of adverse effects of medications for schizophrenia and the development of methods to counteract these side effects. Dr. David Henderson is studying the problem of weight gain and diabetes associated with newer antipsychotic drugs. Dr. Alicia Powell is studying the effects of risperidone on prolactin and reproductive functions in women.

A recent addition to the research group is Dr. Robert Gould, a psychologist with expertise in cognitive behavioral therapy at Massachusetts General Hospital. With a recent NARSAD grant, Dr. Gould will develop and test new cognitive techniques to treat symptoms of schizophrenia that do not respond to conventional treatments.

For several years, the center has offered fellowships for physician research. In July, an additional fellowship will be offered for a psychologist to study cognitive behavioral therapy. Researchers are also collaborating with Dr. Stefan Hofmann of Boston University in a study of cognitive behavioral therapy to treat anxiety in patients with schizophrenia.

At last count, more than 20 research projects were being conducted at the Freedom Trail Clinic and several new projects, including studies involving genetic analysis, are planned. Individuals with schizophrenia or family members are welcome to call the Schizophrenia Research Center at (617) 921-7836 to learn more about research projects. Clinical consultations are also available and can be arranged by calling (617) 912-7800. Donald Goff, M.D., is the Director of the Schizophrenia Research Center and an Associate Professor of Psychiatry at Harvard Medical School.

Eli Lilly Launches Scholarship Program

Eli Lilly, a pharmaceutical corporation in Indiana, is launching a scholarship program to help people with schizophrenia pursue educational opportunities usually not affordable without financial assistance. Education ranges from vocational training to four-year degree programs.

The Schizophrenia Reintegration Scholarship program is the first of its kind. It is designed to help individuals suffering from schizophrenia pursue their educational objectives, while managing their disease. The innovative program provides people with mental illness opportunities to develop self-esteem and confidence.

Schizophrenia research has led to many scientific advances for treating this disease. With these advances and innovative treatments those suffering from schizophrenia or more likely to return to healthy productive lives. In a recent hearing before Congress, Laurie Flynn, executive director of the National Alliance for the Mentally Ill, testified that the success rate for treating schizophrenia has moved up to 60 percent.

This success rate encourages those suffering for schizophrenia to return to every day activities. The scholarship programs will help defray costs in educational programs such as:

- graduate degrees
- bachelors degrees
- associate degrees
- undergraduate professional degrees in fields such as nursing or social work
- trade or vocational school programs
- high school equivalency programs.

Applicants must be diagnosed with schizophrenia and currently be receiving treatment for the disease. Eli Lilly has appointed an independent panel of experts in the treatment of psychiatric illnesses to select the scholarship winners. Winners will be notified by May 15. For more information, contact the Eli Lilly Scholarship Office at 847-705-4970, or email: zyschol@aol.com.

The DMH Bulletin

A quarterly publication of the Massachusetts Department of Mental Health, reporting state news and relevant information for clients and their families, mental health professionals, vendors of services, and all citizens interested in the goals and mission of this Human Service Agency.

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Address Correction Requested

The DMH Bulletin

Massachusetts Department of Mental Health Vol.1 No 14 Summer 1998

The Brudnick Institute (right) connects to the Bryan Building in this architect's sketch.

Brudnick Neuropsychiatric Research Institute Takes Shape at State Hospital

A $12 million, 32,000 square-foot neuropsychiatric research institute, constructed for the University of Massachusetts Medical Center adjacent to the Bryan Building at Worcester State Hospital, is taking shape. Front-end loaders and bulldozers have cleared the site and construction is under way.

The state-of-the art structure, financed in large measure -- $7.8 million -- from the Department of Mental Health, will be connected to 20,000 square feet of renovated Bryan Building space. The Department of Psychiatry at the University of Massachusetts Medical Center in Worcester will direct research into the biological causes, diagnoses and treatment of chronic and serious mental illness.

At groundbreaking ceremonies June 16 inside a large tent, Governor Paul Cellucci said the Irving S. and Betty Brudnick Institute for Neuropsychiatric Research "will help ensure that Massachusetts remains in the forefront in discovering the causes of mental illness and developing new treatments for patients, while strengthening UMass Medical Center's already top-tier research efforts. Over the last few years, we have made considerable advancements in the study and treatment of serious mental illness. This progress has dramatically improved the lives of thousands of mentally ill people. Of course, break-

Turn to **(UMASS)** on page 3

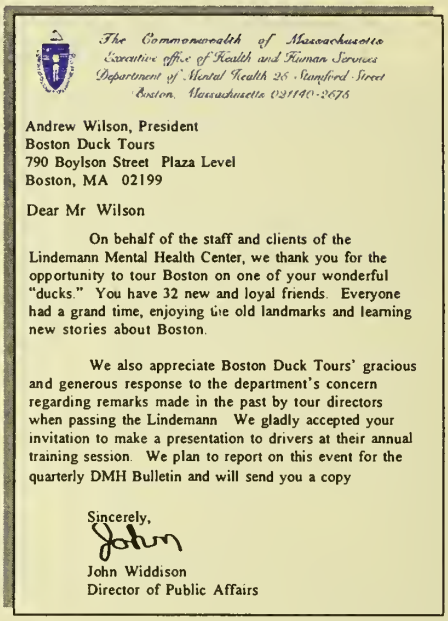
Inside This Issue:

STIGMA TAKES A HOLIDAY

When the Department of Mental Health began receiving complaints from people who had taken trips on the entertaining and educational DUCK TOURS of Boston, we wrote to Tours' President Andrew Wilson. Some of the tour drivers of the amphibious vehicles were making inappropriate remarks about the building, its clients, and services.

We explained that because of widespread misperceptions about mental illness, DMH Commissioner Marylou Sudders had launched a major campaign called "Changing Minds," to raise public awareness of psychiatric disorders, improve understanding, and encourage greater acceptance of treatment. We asked Wilson to help us in this task.

Wilson responded promptly, apologized for any unintended disrespect and promised distribution of a notice to all conDUCKtors that any such comments should cease immediately. He also invited clients and staff to take a complimentary DUCK TOUR.



The Commonwealth of Massachusetts
Executive office of Health and Human Services
Department of Mental Health 25 Staniford Street
Boston, Massachusetts 02114-2575

Andrew Wilson, President
Boston Duck Tours
790 Boylson Street Plaza Level
Boston, MA 02199

Dear Mr Wilson

On behalf of the staff and clients of the Lindemann Mental Health Center, we thank you for the opportunity to tour Boston on one of your wonderful "ducks." You have 32 new and loyal friends. Everyone had a grand time, enjoying the old landmarks and learning new stories about Boston.

We also appreciate Boston Duck Tours' gracious and generous response to the department's concern regarding remarks made in the past by tour directors when passing the Lindemann. We gladly accepted your invitation to make a presentation to drivers at their annual training session. We plan to report on this event for the quarterly DMH Bulletin and will send you a copy

Sincerely,

John Widdison
Director of Public Affairs

Our thanks are extended to Wilson for helping to "Change Minds" about mental illness and to the conDucktours for a wonderful outing June 19 for Lindemann staff and clients. This is STOP STIGMA at work.

(UMASS) con't from page 1

throughs in treatment only come from quality medical research."

DMH Commissioner Marylou Sudders spoke of the hope that the research center brings to the mentally ill. "It is a time to herald the future. With construction of this research institute comes the promise of far-reaching advances that will improve the lives of thousands of people with mental illness. Clinical services alone are not enough. They must be supported by research. It is the only way we can provide effective treatment and ultimately prevent these afflictions.

"This project will complement the work done at our existing Research Center for Excellence at UMass and underscores the continuing partnership between DMH and the University of Massachusetts," she said.

"The Brudnick Institute will bolster the medical center's growing reputation for cutting-edge research and will attract more topnotch scientists to Central Massachusetts," said UMass President William Bulger. The Brudnicks' donation of $2.5 million continues their philanthropic support of the UMass Medical Center's work in psychiatry. They also have provided a $1 million endowment for the Irving and Betty Brudnick Chair of Psychiatry at UMass, now held by Dr. Anthony J. Rothchild, director of clinical research in the UMass Department of Psychiatry. The balance of the project financing will be provided through private contributions.

UMass Medical Chancellor Dr. Aaron Lazare described the Brudnicks as "true friends of the university, true benefactors of those with mental illness, and true supporters of scientists who struggle to understand the complexities of the human brain." Surrounded by his children and grandchildren at the groundbreaking, Brudnick said, "I believe in giving back to the community ... Such events as this validate my life."

Claudia Gibson, a DMH Human Rights Advisory Committee member, and Brudnick, who at age 70 has suffered from depression for more than 50 years, addressed the stigma attached to mental illness with pleas to fight it at every turn. "The next time a person makes a stereotypical comment in casual conversation, seize the opportunity to do a little educating," Brudnick said. "It is time to stop being ashamed of being mentally ill," Gibson said.

UMass hopes to add 10 new researchers in the field of neuropsychiatry and attract $4 million to $5 million in grants for projects conducted to determine the causes, diagnoses and treatment of chronic and serious mental illness, according to Dr. Lazare. He said the center will be one of 10 to 12 such facilities across the country devoted strictly to biological research into the causes, diagnoses and treatment of serious mental illness.

The institute will contain labs, space for test animals, offices, a library, and a conference center. The Division of Capital Planning and Operations is managing the construction project; Fontaine Bros. Inc. of Springfield is the builder.

The Brudnick Institute will serve not only as a state-of-the-art research facility, but as a source of excellence in clinical care of people with mental illness and a center for the education of mental health professionals. Although the UMass Department of Psychiatry will provide leadership for the new institute, it is expected that the research efforts and the existing neuroscience research at the DMH Center for Excellence at UMass will be mutually enhancing.

The Department of Mental Health's Center for Psychosocial and Forensic Services Research at the UMass Medical Center conducts studies that advance the relationship between behavioral science and clinical practice. Specifically, this Research Center for Excellence is:

- designing and conducting studies which contribute to how individuals with serious mental illness and their families interact with the forensic and criminal justice system;
- designing and conducting studies that measure the effectiveness of techniques to improve the recovery and rehabilitation of individuals who have severe and persistent mental illness; and
- designing a system to determine the research needs and interests of DMH priority clients.

Conference Updates...

Curriculum and Training Committee Conference, May 22, 1998, Boston University, Center for Psychiatric Rehabilitation.

The Department of Mental Health (DMH) and the National Alliance for the Mentally Ill (NAMI) of Massachusetts first established a training committee in response to a survey in 1991, which showed that more than half (53%) of clinicians from the core mental illness professions -- psychiatry, psychology, social work and psychiatric nursing -- were still teaching a theory of family causation of serious mental illness. A curriculum and training brochure at the time stated, "It is time for the winds of change to blow into academia." And blow they did. Alabama, California, Maryland, Nebraska, New York, and Pennsylvania, along with Massachusetts, undertook ways to influence professional education.

The subject of this year's annual training conference at Boston University was recovery and rehabilitation for people experiencing alcohol/substance abuse and mental illness. It was chaired by Lois Pulliam, MA, from NAMI of Massachusetts, and LeRoy Spaniol, Ph.D., executive publisher of the Psychiatric Journal, B.U. Center for Psychiatric Rehabilitation. Ken Minkoff, M.D., of

Turn to **(DUAL)** on page 9

NAMI of Masachusetts Annual Meeting May 9, 1998, DoubleTree Hotel, Lowell, Massachusetts.

Telling his audience that the National Alliance of the Mentally Ill (NAMI) has made a difference "in the world," and that if it were not for the Alliance, clozaril might not be on the market, David Pickar, M.D., chief of the Intramural Research Program at the National Institute of Mental Health, challenged families, consumers and clinicians -- "Don't be satisfied with stability!"

Working with the psychotic disorders chart (on the next page) Pickar asserted that the more recent neuroleptics, the so-called "atypical antipsychotic" medications, are widely underused. Fifty percent of individuals with schizophrenia still attempt suicide and 20 percent die from suicide. "Schizophrenia is not rare; 1 in 100 Americans have schizophrenia, more than Alzheimer's, multiple sclerosis and diabetes combined."

As with all other illnesses, the time has come for mental illness to be treated as an illness, in insurance coverage, in first-line medications, and in its search for a cure. The Psychotic Disorders chart tells the story.

Conferences Coming Up...

Early Interventions in Psychosis, an annual clinical conference sponsored by the Massachusetts Department of Mental Health and its two Research Centers, September 17-18,1998, at the John F. Kennedy Library, Boston.

To register, call Judith Conroy, 508-856-5518 after August 1.

Northeast USA Clubhouse Conference, a three-day conference sponsored by the Massachusetts Clubhouse Coalition, October 14, 15, 16, 1998, Sheraton in Springfield.

For more information, call Mike Demers, Genesis Club, 508-831-0100.

PSYCHIATRIC DISORDERS
Recovery Chart

	Active Illness *Danger to Self or Others*	**Active Illness** *Controlled Psychosis*	**Stable But Not Improving**	**Stable & Improving**	**Normalized Activity**
INITIATING ADVOCACY	no advocating no future goals	comfortable in institution not complaining	**voicing own desire more goals more present than future**	improved sense of self goals present & future focused	plans and executes long term goals
Staff Supervision Needed	HOSPITAL WARD locked ward 24 hour nursing care	CUSTODIAL CARE unlocked ward day hospital partial hospital	**COMMUNITY RESIDENCE STAFF** **rehab. house** **3/4, 1/2, 1/4 house**	STAFF SUPPORTED APARTMENT includes other's home	INDEPENDENT LIVING own apartment flexible support from staff
POSITIVE SYMPTOMS OF ILLNESS	POTENTIAL FOR VIOLENCE high VOICES present most of time, unpleasant THINKING bizarre, unpleasant REALITY TESTING poor KNOWLEDGE RE: ILLNESS poor	POTENTIAL FOR VIOLENCE not a present concern VOICES present most of time unpleasant THINKING less bizarre, unpleasant REALITY TESTING fair KNOWLEDGE RE: ILLNESS poor	**POTENTIAL FOR VIOLENCE** **minimal** **VOICES** **present most of time** **unpleasant** **THINKING** **more organized, unpleasant** **REALITY TESTING** **more reality based** **KNOWLEDGE RE: ILLNESS** **fair-some denial**	POTENTIAL FOR VIOLENCE minimal VOICES less intrusive, viewed as part of illness THINKING organized, goal directed REALITY TESTING reality based most of time KNOWLEDGE RE: ILLNESS fair, less denial	POTENTIAL FOR VIOLENCE not an issue VOICES none or minimal THINKING organized, goal-direct REALITY TESTING good KNOWLEDGE RE: ILLNESS good
NEGATIVE SYMPTOMS OF ILLNESS	FACIAL EXPRESSION distressed, anxious, flat SPEECH monotonous voice INTEREST IN OTHERS avoids close relationships	FACIAL EXPRESSION distressed, anxious, flat SPEECH begins to initiate conversation INTEREST IN OTHERS does not initiate relationship	**FACIAL EXPRESSION** **less distressed, anxious** **SPEECH** **better tone, volume** **INTEREST IN OTHERS** **show interest in others**	FACIAL EXPRESSION demonstrates spontaneous humor SPEECH give &take dialogue INTEREST IN OTHERS cooperates with others	FACIAL EXPRESSIONS full range of expressions SPEECH good conversation INTEREST IN OTHERS enjoys relationships with others
WORK& EDUCATION	VOLUNTEER WORK very limited concentration for task poor cleaning own area minimal	VOLUNTEER WORK more time w/task improved concentration cleaning own area	**VOLUNTEER WORK** **day treatment programs** **psychosocial rehab.** **sheltered employment**	VOLUNTEER WORK TEP *1/2 time, 1/2 club.* supported education job training	VOLUNTEER WORK indep. employment P/T, F/T indep. education indep. volunteer
HYGIENE & SOCIAL SKILLS	PERSONAL HYGIENE poor SOCIAL SKILLS poor	PERSONAL HYGIENE grooming, hygiene poor SOCIAL SKILLS eye contact body language poor	**PERSONAL HYGIENE** **increased interest in grooming** **SOCIAL SKILLS** **increased eye contact, smiling better non-verbal comm.**	PERSONAL HYGIENE good attention to grooming SOCIAL SKILLS good	PERSONAL HYGIENE good personal presentation SOCIAL SKILLS normal

Source: The National Alliance for the Mentally Ill of Massachusetts Medication Task Force and Novartis Pharmaceuticals.

(From left), Marylou Sudders, Karen Engell, Director of Health Service Mount Holyoke College, Rosalynn Carter, and Karen Jocobus Coordinator of Health Education at Mount Holyoke College in South Hadley.

Former First Lady, Rosalynn Carter, Speaks at Mt. Holyoke About Her New Book: *Helping Someone with Mental Illness*

The first thing you need to know is that life isn't over. "The good news," says Rosalynn Carter, "is that with proper diagnosis and treatment, the overwhelming majority of people with mental illness can now lead productive lives." DMH Commissioner Marylou Sudders introduced Mrs. Carter to a packed audience in the Chapin Auditorium on the campus in South Hadley on May 6, 1998.

The "Changing Minds Campaign" of the Department of Mental Health delivers much the same message. "Mental illness is an illness. It is not a character flaw. It is an illness that should be treated in the same way that ailments such as heart disease and diabetes are treated," said Sudders. A public opinion survey, commissioned by the Department, confirms that misinformation is the main reason why people do not see mental illness as an illness ... and "stigma prevents individuals from seeking treatment," she added.

Based on her 25 years of advocacy and the latest research from the Rosalynn Carter Symposia for Mental Illness, Mrs. Carter's book addresses the latest breakthroughs in understanding, research and treatment of major mental illnesses. Steven Hyman, M.D., Director, National Institute of Mental Health, says, "This is a book that will inform and offer hope to individuals and families who today are grappling with the still grim realities of disabling mental disorders."

Helping Someone with Mental Illness will also help in "Changing Minds."

Briefly Noted...

HISTORY OF DSM

Since the 1950s, the Diagnostic Statistical Manual (DSM) has shaped the practice of psychiatry -- more than some might like -- by providing a widely agreed upon nomenclature as a basis of communication. This need was apparent to the founders of the American Psychiatric Society (APA), originally known as the Association of Medical Superintendents of American Institutions for the Insane.

In 1849, Isaac Ray, the superintendent of Butler Hospital in Rhode Island, disputed psychiatric hospital statistics, saying, "Until some system is adopted ... no one can be sure that terms such as melancholia are understood precisely by all who use the terms." By 1917, the Association had established a committee that resulted in the Statistical Manual for Mental Diseases. It underwent numerous revisions until 1952 when the first DSM was published by the APA.

- DSM-I maintained the coding system used in the earlier manuals and included brief descriptions of terms.
- DSM-II, published in 1968, was an effort to coordinate with the International Classification of Diseases (ICD) produced by the World Health Organization.
- DSM-III (1980) reflects major changes in thinking about mental illness. The term "neurosis" disappeared and "involutional melancholia" became "depression."
- DSM-IV (1994) is a product of new research data; it is an effort to create clearer criteria. It is also the first step in preparing for a new ICD.

MORE HISTORY... NIMH THE NATIONAL INSTITUTE of MENTAL HEALTH

The federal government entered the mental health field in 1946 with the passage of the National Mental Health Act. It authorized the National Institute of Mental Health (NIMH). More than 100 years after Dorothea Dix sought support for psychiatric hospitals, the government's concern about drug addiction produced the Harrison Narcotics Act in 1914. Federal hospitals followed in 1929 at Lexington, Ky., and Fort Worth, Texas. The Narcotics Division within the Public Health Service was created in 1931 and renamed the Division of Mental Health.

World War II sidetracked the grand vision of the center called the National Neuoropsychiatric Institute to be modeled after the National Cancer Institute and the National Heart Institute. The war did focus attention on the many people rejected for military service because of mental disorders and later, on the toll of war casualties, especially the large numbers of veterans with psychiatric problems. The time was ripe for NIMH.

The first congressional appropriation did not occur until 1949. Since then, NIMH has provided billions of federal dollars for research and training. Under its activist director, Steven Hyman, M.D., NIMH today looks to a future of prevention, recovery and eventually for cures of mental illnesses.

After Lab, Computer, and Animal Models ... Human Trials Needed for Research

By Maire Hermann, M.A.

Medical research involving human subjects makes people uneasy. Although research is necessary for progress, the idea of participating in experiments involving new drugs or procedures is unsettling. Many years ago, research subjects were not informed that they were part of an experiment. But when illness strikes and patients find themselves in a "no known cures" area, the clamoring begins for more research. At the same time, individuals who agree to be subjects in experiments come into focus.

How should individuals and their rights be protected while continuing research?

Scientific researchers are trained to follow the rules of their discipline and the laws of statistics when drawing conclusions from studies. When research involves human subjects, society demands additional rules to protect those involved. Research steps from the quantitative realm of science, where results can be measured, to the realm of ethics and morals, where judgments are qualitative and subjective. Rules are harder to define and to police.

The federal government has tried to provide oversight for research involving human subjects by requiring that proposals be approved by an Institutional Review Board (IRB) comprised of professionals and laymen. The hope is that the collective judgment of such a group will afford protection for human research subjects. The IRB is charged not with judging the science involved, but with protecting subjects.

Such an IRB meets for two hours every month at the Department of Mental Health to review all proposals for research involving DMH clients. All members of the IRB volunteer their time.

Several days before board meetings, members review material. To show how the committee works, consider a recent protocol for an "Adjunctive Treatment of Schizophrenic Patients with Ginkgo Biloba Extract: a Double-Blind Parallel Study With Placebo."

In the protocol, the researcher discusses cognitive impairment as an aspect of schizophrenia and writes that "present data suggests that the available drugs used in treatments of schizophrenia are not effective cognitive treatments." In European research, Ginkgo Biloba Extract (GBE), a food supplement, has been shown to improve memory and concentration in normal volunteers and in patients with dementia. In Massachusetts, a preliminary clinical trial was conducted with 10 psychiatrically stable patients with schizophrenia, and the results were positive enough to warrant further study. This led to a National Alliance for Research on Schizophrenia and Depression (NARSAD) grant that will fund this protocol's study. There is reason to hope that GBE might improve cognitive performance on tasks involving memory and attention. This background information was important to help the IRB assess whether this research might benefit clients of the Department.

Recent Proposals Brought Before Review Board

•Compare the efficacy of olanzapine, risperidone and haldol for cognition in schizophrenia

•Housing initiative to evaluate housing approaches for persons with serious mental illness

•Study of end of life care for persons with serious mental illness

•A multi-center, placebo controlled study of the safety and efficacy of a new drug referred to as M100907

The study, spanning eight weeks, would include a group of 60 clinically stable clients, diagnosed with schizophrenia, who would be assessed, cognitively and psychiatrically, at the start. Then, they would be randomly assigned to either a group recieving GBE or to a group receiving a placebo. Since the use of placebo, in this case, did not involve leaving illness untreated, the

Turn to **(IRB)** on page 12

(DUAL) con't from page 4

Choate Health Management and Arbour Health Systems, the keynote speaker, presented "An Integrated Model for People with Mental Illness and Alcohol/Substance Abuse." Since most systems of care are designed for people with only one disorder, most consumers see themselves as system misfits. "We make people fit the system, not the system fit the people," said Dr. Minkoff. "Both diagnoses should be considered primary."

A 1994 study of Massachusetts' Medicaid carve-out found that 80% of the program's highest users were dually diagnosed. "Dual diagnosis is an expectation, not an exception. Services for this population need to be developed at the community level where a clinician or team of clinicians must stay with the person over time, through multiple episodes in multiple settings to develop the skills necessary for recovery of both disorders," Dr. Minkoff said.

The second keynoter, Harriet Lefley, Ph.D., spoke on "The Impact of Dual Diagnosis on Families." "What is most painful for family members is the suffering of people they love, particularly the lost developmental stages of learning and a life that does not match their talents and intelligence ... to balance love and anger: to swing between empathic pain and frustration with someone who is obviously ill, but denies illness, rejects treatment and causes trouble." Lefley reminded the audience of providers, families and consumers that recovery is not remission, nor is it a return to a preexisting state. The idea of being "cured" is counterproductive to recovery, which is the development of a new ego and a new and healthier personality and lifestyle that is strong enough to stand on its own.

Rather than seeking a devalued identity, many people with mental illness are beginning to appreciate their own courage in living with and overcoming the traumas of symptoms and stigma. Lefley suggests this can occur mostly within consumer organizations that offer peer support and role models and provide something that families and professionals cannot -- the exemplification of coping strengths and a vision of the possibilities of living a satisfying life.

Moe Armstrong, MBA, MA, spoke of one such consumer whose life, once wracked by the symptoms of schizophrenia and substance abuse, now offers a vision of hope. Armstrong's story was his own. Today, Moe Armstrong is the Director of Consumer Affairs for the Vinfen Corporation, a provider of programs and residences for people with mental illness. He has earned advanced degrees and is a member of the DMH/NAMI Curriculum and Training Committee.

After processing and editing, a video tape of this conference will be available from the DMH video library. Call Public Affairs at (617) 727-5500 ext. 436.

The DMH *Bulletin*

A quarterly publication of the Massachusetts Department of Mental Health, reporting state news and relevant information for clients and their families, mental health professionals, vendors of services, and all citizens interested in the goals and mission of this Human Service Agency.

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SCHIZOPHRENIA and SCHOLARSHIP

For four consecutive semesters at Boston University, "I was not manic. I was not homeless. I was not a mental patient or an ex-mental patient. I was a STUDENT! And it felt great!" Once classified by himself and his caregivers as a "lifer" -- someone who would spend the rest of his life in a hospital -- today Gaston Cloutier is a supported education counselor for CAUSE (Consumers & Alliances United for Supported Education) at the Quincy Mental Health Center. He was recently appointed to the Human Rights and the Seclusion and Restraints Committees of the same hospital that in the early 1980's he had no hope of leaving.

CAUSE is a supported education program that assists and encourages individuals with psychiatric disabilities to enter or return to college or to technical school programs. Although sponsored by the Department of Mental Health, as well as the National Alliance for the Mentally Ill of Massachusetts, any person with a mental illness may participate. The CAUSE committee, made up of consumers, interested parties and professionals, has watched not only the growth of self-respect, confidence and initiative in the participating students, but a visible reduction of stigma in the academic community.

In addition to CAUSE, the Lilly Schizophrenia Reintegration Scholarship Program is designed to help individuals suffering from schizophrenia, yet managing their disease, to pursue their educational objectives, including:

- graduate degrees
- bachelors degrees
- associate degrees
- professional degrees in fields such as nursing or social work
- trade or vocational school programs
- high school equivalency programs

Gaston Cloutier of Ashland is one of the 51 aspiring students selected out of more than 1,800 applicants who received letters this Spring which read, "I am pleased to inform you that you have been selected to receive a 1998-99 Lilly Reintegration Scholarship."

Cloutier's high school honors ranged from being class president three out of four years, member of several sports teams, debating team captain, and National Honor Society member to being designated an Outstanding Teenager of America listed in the "Who's Who in American High Schools." But during his first year at Cornell, Cloutier began experiencing deep depression and manic highs, eventually leaving college and losing his scholarship.

For more than 20 turbulent years, Cloutier has been homeless, hospitalized, jailed and suicidal. He then looked into the Boston University Pschychiatric Rehabilitation Program. It was there he first began to feel "like a person not a patient." From B.U. to Massachusetts Bay Community College to a B.A. in Liberal Arts from Framingham State College, Cloutier is now a man with meaningful employment and a wonderful wife, Christine.

Now his goal is to continue his education through Catholic University's Distance Program and thanks to Lilly's Reintegration scholarship, that is set to happen, starting this fall.

For more information:

CAUSE
Quincy Mental Health Center
460 Quincy Avenue
Quincy, MA 02169
(616) 770-4000 ext. 297 or 273

Lilly Scholarship Office
PO Box 1223
Palatine, IL 60078-1223
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Consumer/Survivor Conference

By Steve Holochuck

The Office of Consumer and Ex-Patient Relations (OCER) sponsored 14 consumer/survivor leaders from across the state at the Alternatives '98 Conference in Long Beach, CA. Alternatives '98 is the annual national gathering of the mental health consumer/psychiatric survivor/ex-patient movement.

Hundreds of mental health consumers from across the country and abroad attended the four-day conference. It offered presentations, workshops, and caucuses dealing with recovery, self help, empowerment, advocacy, alternative approaches, managed care, consumer employment in mental health, and diversity, among other issues. The Massachusetts delegation included members of the DMH Consumer Council and the Massachusetts Coalition of Mental Health Consumer/Psychiatric Survivor Organizations.

Hundreds of mental health consumers from across the country and abroad attended the four-day conference.

On the first day of this year's conference, the delegation attended the institute entitled, "Take Charge of Your Mind: Crisis Prevention/Self-Healing and Community Organizing for Activists/Leaders." Facilitators emphasized the importance of combining a rich support network with the challenge of building powerful consumer/survivor organizations.

Throughout the conference, participants gathered at general sessions to hear featured speakers. Irit Shimrat, a psychiatric survivor and author of Call Me Crazy: Stories from the Mad Movement, shared her experiences and ideas. She stressed the importance of self-definition and self-determination in building a liberation movement. The following day, Jacki McKinney, a consumer/survivor who has dedicated much of her activism to the issues of women of color, spoke. She discussed the connection between racism, stigma, poverty, oppression, violence, and institutionalization.

Workshops included the discussion of such topics as peer consumer satisfaction teams, approaches to influencing policy and planning, the media, human rights, and art and culture. Sample workshop titles encompassed "Moving from Disability to Work," "Organizing a Human Rights Campaign Around a Psychiatric Institution," and "Managing a Local Drop-In Center." Howard Trachtman, a member of the Massachusetts delegation, presented two workshops: "Using the Internet for Networking and Support" and "Entrepreneurship '98."

Evenings provided opportunities to relax and socialize. Evening caucuses were held for constituencies such as Internet users, self-help organizers, and gay/lesbian/bisexual/transgender people. Throughout the conference, delegation members staffed tables in the exhibition hall highlighting consumer/survivor activities in the Commonwealth.

Participants attended an open-mike wrap-up session on the last morning of the conference. The Massachusetts delegation gathered a number of times to discuss how to utilize what was learned from conference presentations and informal networking. The consumer/survivor leaders returned to Massachusetts eager to share and apply the lessons learned at Alternatives '98.

Steve Holochuck is Director of the Office of Consumer and Ex-Patient Relations.

(IRB) con't from page 8

board had no misgivings.

Members of the IRB pay particular attention to recruitment procedures to be certain patient privacy is protected and that no coercion is involved. In this study, clinicians at specific sites would be contacted and informed about the study and the criteria for including and excluding individuals. The clinicians would recommend patients appropriate for the study. Then either the clinician or research team would assess which patients would participate. As the researcher put it, "If a patient agrees to participate, with the help of clinical staff we will determine whether the patient is competent to provide informed consent. We will be reiterating, on a continuing basis, the subject's right to withdraw from this study or to refuse the study medication or procedure." The researcher obviously understands and respects the population involved.

The side effect profile for GBE was also considered. It has been studied extensively with large numbers in Europe and the risks involved are minimal. "There are a few reports suggesting that GBE may increase bleeding time, particularly in patients that are taking coagulants." Such patients would be excluded from this study or included only with the collaboration of an internist/hematologist. Because of this possible side effect, prior to the study, the patients would receive a physical examination and blood work that would include measuring bleeding time. This blood work would be repeated at the fourth and eighth weeks. Physicians on the IRB would also react to anything medically dangerous. The researcher wrote that although GBE "is known to be a very safe compound, unexpected side effects may occur. If there are serious unexpected side effects, the patient will be withdrawn from the study immediately and appropriate medical attention will be sought." The unforeseen was being considered and the patient protected.

The IRB requires that study subjects be given telephone numbers to reach research doctors. This protocol went further and would contact "the patient by phone or face-to-face each day the study drug is increased, and for the following two days after the dose increment." Also, the research team would educate the patient's treating staff (i.e., patient's case manager, psychiatrist, or psychotherapist) so they could monitor and alert the research team about any unwanted adverse reactions. Communication with those who interact with the patient, a step that minimizes risk, is not always indicated in protocols.

Care had been taken to write the consent form in layman's terms, fully explaining procedures, not understating risks nor overstating benefits. The time involved in each assessment was stated. The name and number of a human rights officer was given in the event the subject wanted to talk to someone who wasn't involved in the study.

The form explained that after the eighth week of treatment, GBE would no longer be provided but could be purchased at any health food store. The IRB wanted the researcher to add that this should be done in consultation with the person's physician. With this one change, the protocol was approved. The researcher must report any mishaps to the IRB and must submit a final statement concerning the project.

This protocol was easier to deal with than others because it included all of the precautions required, the consent form was complete and well written, and the potential benefits clearly outweighed the minimal risks. The discussion and approval took about 20 minutes.

In the end, it is the research team which must follow through on what has been spelled out. There is always the risk of careless work or human error, but the process of the IRB reminds researchers that whenever people are involved, utmost caution is necessary, especially when the psychiatrically disabled are included in research. There must be appropriate attention to respect and protection.

Marie Hermann, M.A., is a lay member of the Institutional Review Board, former Family Support Organizer of the National Alliance for the Mentally Ill, and the mother of a son with mental illness.

Walking the Walk

On May 2, 1998, more than 4,000 people walked the "Walk for Lives Touched by Mental Illness," a one-mile event, the first ever march in Washington, D.C., for and with people with mental illness. Although the day was one of a 12 day streak of rain in the nation's capital and the Church of Scientology was out in full force with their walkie-talkies and anti-psychiatry and anti-parity posters, nothing dampened the enthusiasm of the crowd. It had come from across the country to raise awareness about mental illness, to demand equal health care, to dispel the misconceptions about brain disorders and to cheer loudly at the words of Surgeon General David Satcher, M.D., who said that we must make mental health a priority.

Hundreds participated from Massachusetts, including 60 people from the Massachusetts Clubhouse Coalition, and the Commissioner of the Department of Mental Health, Marylou Sudders.

Commissioner Sudders at the Walk the Walk in Washington D.C., with members of the Massachusetts Clubhouse Coalition.

National Depression Screening Day.....October 8, 1998

National Depression Screening Day began in 1991 with 90 sites. It now has more than 2,800 nationwide and allows individuals to receive a confidential screening administered by volunteer mental health professionals. Depression afflicts one in ten adult Americans every year ... more than 17 million people. This day is one step in fighting an illness that costs the American economy more than $43 billion per year.

The Signs of Depression

- √ Sad or depressed mood
- √ Sleeping too much or too little
- √ Changes in appetite
- √ Difficulty in concentrating or making decisions
- √ Loss of pleasure in activities formerly enjoyed
- √ Feeling of worthlessness or guilt
- √ Lack of energy or unexplained fatigue
- √ Thoughts of death or suicide

RESEARCH UPDATE

Searching For Neurobiologic Clues in Schizophrenia

By Francine M. Benes, M.D.

The Winter 1998 DMH Bulletin presented brain imaging studies and their role in learning more about how the brain may be wired incorrectly in people with schizophrenia. This issue of the Bulletin will explore some of the specific ways in which changes in intricate neural networks may be altered in schizophrenia.

Researchers have been asking whether there are specific regions of the brain that may be particularly affected in schizophrenia. The short answer is yes. Although the brain is a large and complex organ, it is subdivided into many different components, each contributing in specific ways to the behaviors exhibited in a typical day. There are areas of the brain prominent in speaking, walking, focusing attention, and experiencing emotions, to name just a few of these functions.

Several studies from different research in the United States and England have pointed to one particular region of the brain that may be centrally involved in schizophrenia. This region, called the hippocampus, is located in a larger brain division called the medial temporal lobe. The hippocampus plays an essential role in important functions, such as learning and emotion.

The hippocampus is involved in a type of seizure disorder called temporal lobe epilepsy. When a person is having a temporal lobe seizure, the brain becomes overloaded with activity and this may result in a loss of consciousness. Although a small proportion of schizophrenia patients have seizures, most do not.

With this overlap in the two disorders, it is no surprise there are some clinical similarities between temporal lobe epilepsy and schizophrenia. For example, patients with temporal lobe epilepsy, like those with schizophrenia, have auditory hallucinations. Under stressful conditions, auditory hallucinations become more pronounced in individuals with schizophrenia.

Have you ever seen a person with schizophrenia showing a glazed facial expression and then suddenly running out of a room? At such times, that person may be overwhelmed by sensory stimulation from the surrounding environment. Although people with schizophrenia do not lose consciousness, like patients with temporal lobe epilepsy, they are apt to have an exaggerated degree of activity within their hippocamus.

Is there a specific type of neuron in the hippocampus that could help to explain both the seizures in epilepsy and the sense of being overwhelmed in schizophrenia? The answer: probably. Epilepsy typically involves a type of neuron, called a GABA cell, that is not functioning properly. GABA is a neurotransmitter that has the principle function of stopping other neurons from being too active. This is called inhibition and is essential for the brain to function normally.

Why is inhibition so important? If there is not enough inhibitory activity, the nerve cells in the brain fire too frequently and this results in an entire network or circuit becoming overwhelmed. If the activity of neurons is excessive, they may become exhausted and die. When a patient is having an epileptic seizure, the amount of activity is very extreme, but it is also very time-limited. Most seizures are of minimal duration and are followed by return to a relatively normal level of functioning. This is fortunate because if a seizure continues for a long period it may cause damage to the brain. Prolonged seizures promote further seizures. In schizophrenia, the amount of activation at any given time is much less than is typically seen in epilepsy, but the episodes of acute schizophrenic illness may last weeks or months, rather than minutes. Despite this difference, the episodes that occur early in the course of schizophrenia (i.e. during the first 5-10 years) are often associated with some deterioration in functioning. So, while postmortem

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studies of schizophrenia have not shown the sort of damage seen in patients with epilepsy, the changes that occur in schizophrenia may still be capable of causing subtle damage to the brain.

What does all of this have to do with GABA, the inhibitory neurotransmitter? Both epilepsy and schizophrenia seem to involve a disturbance of GABA cells. When there is too little GABA activity, the responsiveness of an epileptic or a schizophrenic may become excessive.

Is it possible to enhance GABA cell activity in schizophrenia? The medications that are used to treat epilepsy typically improve the activity of the GABA system. When these so-called anticonvulsants (e.g. Klonopin, Depakote and Tegretol) are prescribed for a person with schizophrenia, they are also helpful, but not to the same degree as in epilepsy. One interpretation is that the GABA system in the schizophrenic brain is not as severely affected as it is in epilepsy.

Another interpretation is that GABA may not be the only neurotransmitter that is malfunctioning in schizophrenia. Another transmitter, called dopamine, may also be altered in schizophrenia, because the drugs that are used to treat psychosis block dopamine receptors. Early evidence suggests that antipsychotic medications may act, in part, to block the effects of dopamine on GABA neurons, the inhibitory cells that are abnormal in epilepsy. Some evidence indicates that these drugs may actually enhance the release of GABA in some parts of the brain involved in schizophrenia.

In other words, if GABA cells are receiving too much dopamine input, blocking its effect with drugs like clozapine and Prolixin might make it possible for the GABA cell to fire more normally. This would help to explain why anticonvulsant drugs, although somewhat helpful, are not as effective as antipsychotic medications in treating schizophrenia. In contrast, patients with epilepsy, having a problem with GABA, but not with dopamine, respond better to anticonvulsants. This is why the medications used to treat the two disorders are quite different, even though GABA cells are altered in both.

Based on many studies from laboratories in several locations (including Boston), it appears that several different transmitter systems may be playing a role in schizophrenia. This will make the work of neuroscientists all the more complicated. In order to have a clear understanding of how intricate neural circuits are altered in schizophrenia, it will be necessary to piece together scientific findings from many different types of postmortem studies. This is why brain tissue is essential for research to continue.

Dr. Francine Benes is Professor of Psychiatry (Neuroscience) at Harvard Medical School, and Director of the Harvard Brain Tissue Resource Center, which is located at McLean Hospital in Belmont.

For more information about brain donation, call 1-800-BRAINBANK.
HTTP://Benesville.McLean.ORG:8080/FMB.HTML
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The DMH Bulletin

Massachusetts Department of Mental Health Vol.1 No 15 Fall 1998

From the Commissioner

Mentally Ill Substance Abusers Need Integrated Treatment

By Marylou Sudders

The public has long thought of serious mental illness and substance abuse as more similar than disparate. Through the years, some of those treating individuals with both disorders have insisted otherwise. That is changing.

Individuals with mental illness often self medicate with alcohol or drugs to relieve the symptoms of psychiatric disorders. As a result, they wind up with two problems instead of one.

The Departments of Mental Health, Public Health and the Division of Medical Assistance have been working with key stakeholders over the past year to develop a single model

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of care to treat the dually diagnosed. The model is based on treating both disorders as primary illnesses. They are so intertwined that regardless of when they occur, each illness must be considered as primary and each must receive specific and concurrent treatment.

The National Comorbidity Substance Abuse and Psychiatric Disorders Study, funded by the National Institute of Mental Health, tells us that for people with schizophrenia, 47% also abuse alcohol or drugs, and for persons with affective disorders, 32% have substance disorders. It jumps to 55% for individuals with bipolar disorders. If you have schizophrenia, the odds of abusing alcohol or drugs are 4 1/2 times greater than the general population. Individuals with co-occurring serious mental illness and substance disorders represent a majority of the population now served within DMH facilities and treatment must be current to meet their needs.

Dr. Bernard Arons (from left), Director of the Center for Mental Health Services; DMH Commissioner Marylou Sudders; Dr. Paul Barreira, DMH Deputy Commissioner of Clinical and Professional Services; and Bruce Bullen, Division of Medical Assistance Commissioner, at the State House event.

Our collective wisdom and experience tells us that for people with co-occurring disorders, they ...

- will have more fragmented care if either the mental illness or the substance disorder is undertreated or ignored;

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- overall, there will be more treatment failures;
- there will be more frequent use of emergency and crisis services;
- there will be greater incidence of homelessness;
- we will see increased morbidity from suicide and untreated medical illnesses; and,
- reviews of the literature on patient violence document that substance abuse and mental illness increase the risk of violence and results in greater incarceration in the criminal justice system.

The Department, under the leadership of Dr. Paul Barreira, Deputy Commissioner of Clinical and Professional Services, has long recognized the need for integrated services that assure continuity of care across treatment settings. To this end, DMH, the Department of Public Health (DPH), the Division of Medical Assistance (DMA) and the Massachusetts Behavioral Health Partnership applied for and received one of 21 grants awarded nationally last year by the Substance Abuse and Mental Health Services Administration's (SAMHSA's) Center for Mental Health Services to develop an "exemplary practice" to treat vulnerable populations.

A consensus-building group has successfully developed a single, integrated model of care encompassing inpatient, acute and emergency, day treatment, outpatient, case management and residential services. It offers solutions for specific structural, clinical and ideological differences between mental health and addiction systems. The model calls for specific programs for each phase of treatment of each illness — acute stabilization; engagement, education and persuasion; and ongoing stabilization and rehabilitation.

There is reason for optimism. For example, with standard antipsychotic medication used for individuals with schizophrenia, 70-85% of those experiencing symptoms for the first time find relief. With the newer antipsychotic medications, one-third of the 10-20% of individuals who previously ended up with chronically deteriorating and debilitating illness, respond favorably.

Advances in substance abuse treatment are equally impressive. The American Society of Addiction Medicine has developed adult patient placement criteria for the treatment of psychoactive substance disorders. Targeting treatment has allowed for both the movement of significant amounts of treatment from inpatient to ambulatory care and for improved outcomes.

There have been tremendous recent efforts nationally to address the problem, perhaps because it is becoming clear that individuals with both serious mental illness and substance abuse disorders represent a very high percentage of individuals presenting initially for treatment for either disorder.

DMH, DPH and DMA recognize their responsibility for those with co-occurring serious, chronic and persistent mental illnesses and substance abuse and the opportunity to dramatically improve these individuals' lives through effective intervention.

In addressing the large crowd gathered November 6 at the State House to mark the adoption of principles for a single model of care, DPH Commissioner Howard Koh spoke of a shared vision in describing comprehensive, responsive treatment for individuals with mental illness and substance abuse disorders. "Despite distinctive differences in symptoms, chronic and persistent psychiatric disorders and substance dependence are often seen as examples of illnesses with common characteristics. Both are regarded as having parallel phases of treatment, rehabilitation and recovery, although the recovery processes are usually independent."

Bruce Bullen, DMA Commissioner, said all three agencies "recognize our responsibility for those with co-occurring serious mental illness and substance abuse disorders and the opportunity is at hand to dramatically improve the lives of these individuals through effective intervention." Many individuals with mental illness and substance abuse disorders have coverage through MassHealth, a program administered by DMA, with services provided through the Massachusetts Behavioral Health Partnership. "Through this single model of care, we are encouraging and promoting treatment for individuals with co-occurring disorders," Bullen said

We first started talking about dual diagnosis treatment in Massachusetts in 1973. The Department and its partners are now poised to take the next big step, implementation of a treatment model, in 1999. Completion is expected within the next five years. SAMHSA support looks promising. While implementation will not happen over night, it will happen. Of that, we are sure.

"America's First Doctor" Takes on Stigma

Eliminating the stigma of mental illnesses and ensuring these illnesses are treated on par with other ailments are two of Surgeon General David Satcher's top priorities.

"We've got to change people's attitudes toward mental health. We don't deal with mental health in the same way we do physical health -- we tend to blame the victim," said Dr. Satcher. His office is preparing a report on mental health that should be distributed by the end of next year. He plans to use the surgeon general's "bully pulpit" to help change society's attitudes toward a group of diseases that afflicts 22% of the adult population in a given year, according to the National Institute of Mental Health.

What Can the Department Do When It Sees Stigma at Work?

Under the direction of Commissioner Sudders and guided by the mission of the Changing Minds Campaign, the Department will often seize an opportunity to raise awareness about mental illness and the stigma which discourages people from seeking treatment. The following letter is one way the Department of Mental Health sends its message:

October 15, 1998

Letters to the Editor
Worceser Telegram & Gazette
20 Franklin Street P.O. Box 15012
Worcester, MA 01615 - 15012

Hearing strange sounds from your computer? Dr. Bombay advises, "Not to worry. That's just the escaped mental patient who's been living in your crawl space waiting for just the right moment to murder you in your sleep." (ASK DR. BOMBAY, 10.6.98)

Mental illnesses are brain disorders which affect 14.5 million Americans. About 700,000 -- more than 15% of Massachusetts residents have -- symptoms of diagnosable mental illness.

After the release of a statewide survey indicating 90% of the public believe the stigma of mental illness prevents people from seeking treatment, Marylou Sudders, commissioner of the Department of Mental Health, launched the "Changing Minds" campaign last year to raise awareness about the effectiveness of current treatment and to wipe out discrimination against those with mental illnesses. The campaign has featured public service announcements by Tipper Gore and CBS newsman Mike Wallace, who once feared the "disease of depression would end my career."

Slang words, such as "nuts," "wacko," "funny farm" and subtle and not so subtle pejorative words fuel this stigma. Being a "mental patient" is no funnier than being a heart patient or cancer patient. Columnists have an opportunity to bring understanding to a topic that is widely misunderstood.

Sincerely,
Ann Madigan
Ann Madigan
Anti-Stigma Coordinator

cc: Dr. Emilio Bombay
Fort Worth Star Telegram

Awakenings with New Antipsychotics

By Kenneth Duckworth, M.D.

The explosion of neuroscience developments in this "Decade of the Brain" now provides people with schizophrenia a new generation of antipsychotic therapies. For many, these medications (e.g., clozapine [Clozaril], olanzapine [Zyprexa], risperidone [Risperdal], and quetiapine [Seroquel], produce an improvement over their "old" antipsychotics in terms of side effects and, for some, clinical response. For a select few, however, these medications can produce dramatic improvement, akin to what Sacks (1990) termed an "awakening." These medications create exciting opportunities to use psychotherapy, group work and rehabilitation with a population historically relegated to back wards or triaged to "case management."

As people awaken to a new mental state and a unique set of psychological challenges, our clinical service at the Massachusetts Mental Health Center (MMHC) has become interested in the experience of these robustly responding patients. MMHC has a large population of people on these medications, and the center has a strong tradition of attending to the psychological experience of people with psychotic illness. We interviewed 15 long-term outpatients with schizophrenia or schizoaffective disorder who were living in the community and who had shown significant clinical improvement on these new compounds. Our findings were published in the November/ December 1997 issue of the Harvard Review of Psychiatry.

We found that, because of the extent and longevity of their psychotic symptoms, many awakened patients have experienced a process of psychological redefinition and have confronted developmental tasks that were dormant prior to their improvement. When the hallucinations, tangential thinking or delusions are quieted, patients are "free" to reassess their status in life. The internal world that they have known is considerably different, and the external world has changed from the way it was before the last time they were not dominated by psychotic thoughts or experiences. Based on our interviews and observations of patients from this sample, we put in place a three-part conceptual scheme for the issues that challenge this population:

- Sense of self;
- Sense of connectedness;
- Sense of purpose.

The psychotherapeutic work at hand for some patients is filled with both grief and hope as they come to reassess themselves, their relationships and their purpose in life. Such work is supportive, reality-based and practical, but is also mindful of the psychodynamic concepts of loss, adaptation and defenses. That agranulocytosis or a change in finances could threaten the loss of these essential medications at any time adds to the challenge for patient and therapist alike.

Sense of Self

The struggle to redefine oneself as the psychotic process remits is a staggering task for any patient. Assisting in this task requires considerable therapeutic dexterity. If the work of therapy is to "acknowledge, bear and put into perspective" (Semrad, 1966), then a revised sense of self challenges the therapeutic endeavor to integrate the current mental state with the previous illness history, reviewing losses and setting realistic goals.

One 32-year-old man who was diagnosed with schizoaffective disorder 15 years ago told us: "I had this psychotic pattern of thinking which was usually circular and dealing with one issue at a time, things like what we would agree to be day-to-day reality. My other experience is relating everything to myself subjectively. My brain was preoccupied with discerning whether this is real or this is not real.

"What clozapine has done is to break up this pattern or thought process. I had certain behaviors that I had adopted in dealing with being an inpatient. With clozapine it was .... sort of like waking up. In a lot of ways, the psychosis acted as my defense and was my way of relating to the world for so long. It was a relief initially not to be crazy. But it is also painful ... like being crazy kept me innocent in a way. Sometimes, I can't bear the weight of my own grief."

This process of integration of a healthy identity with a hopeful future is even more difficult when patients hit a ceiling in their recovery. Such is the case with one 33-year-old woman who began to have auditory hallucina-

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Two Research Centers of Excellence....

The Center for Psychosocial and Forensic Services at the University of Massachusetts Medical Center in Worcester and The Commonwealth Research Center at the Massachusetts Mental Health Center in Boston are funded by DMH. They bring together some of the best minds and talent in Massachusetts to advance treatment and rehabilitation methods for chronic, persistent and severely psychiatrically ill patients. The Center at the University of Massachusetts Medical Center concentrates on Behavioral and Forensic Services. The Commonwealth Research Center focuses on Clinical Neuroscience and Neuropharmacology. This issue of the Bulletin presents an article from the Commonwealth Center on dual diagnosis.

SCHIZOPHRENIA and SUBSTANCE ABUSE OFTEN FELLOW TRAVELERS

Comorbid (joint incidence of illness) substance disorders and schizophrenia: The possible role of antipsychotic medications

By Ellen S. Burgess, Ph.D., Suzannah V. Zimmet, M.D., and Alan I. Green, M.D.

Many studies indicate that patients with schizophrenia often experience problems from the use of various substances; the rate of problematic substance use is substantially higher in patients with schizophrenia than in the general population. A National Institute of Mental Health (NIMH) survey indicated that 47% of patients with schizophrenia have serious problems with substance abuse, compared to 16% within the general population.

Substance use in patients with schizophrenia increases the frequency of relapses, hospitalizations, violence, and noncompliance with treatment. This leads to a poorer overall response to standard antipsychotic medications. Moreover, given the belief that long-term psychotic symptoms result in deterioration of a patient's condition, the presence of a substance disorder in a person with schizophrenia would appear to lead to a worse long-term outcome than might otherwise be expected.

The reason for the use of substances by patients with schizophrenia is not entirely clear. The "self-medication" hypothesis suggests that patients use substances to remedy a clinical problem. A number of investigators have suggested that in patients with schizophrenia, substances may be used to limit negative symptoms or antipsychotic drug-induced side effects. While this hypothesis is supported by data indicating that substances may decrease negative symptoms, such as social anxiety, loss of pleasure, apathy, or shyness in patients with schizophrenia, there are no studies directly confirming that substance abuse occurs because of negative symptoms or drug side effects.

Another way of thinking about the reason for abusing substances in this population involves the possibility that it may correct dysregulations in brain pathways related to the loss of pleasure that many patients with schizophrenia experience. Such dysregulations may be modified and transiently lessened by the effects of abusing substances.

Whatever the basis for the substance use, it is well known that treatment of patients with substance disorders and schizophrenia is extremely difficult. While standard antipsychotic medications are effective for psychotic symptoms, they do not appear to limit substance abuse.

Interestingly, the antipsychotic drug clozapine may have a different clinical therapeutic profile in this population. Preliminary studies at the Commonwealth Research Center at the Massachusetts Mental Health Center and other sites suggest that clozapine use is associated with substantial reductions in alcohol and other substance use in these patients. While the basis for the apparent unusual effect of clozapine in this population is unknown, it is possible that the medication's effect may be related to its ability to relieve negative symptoms, or to its relatively benign neurologic side-effect profile. It may also have biologic effects that directly improve dysregulations in brain pathways that might lead to substance use.

Clearly, further research is needed to clarify whether some or all of the novel antipsychotic medications (clozapine, risperidone, olanzapine and quetiapine) are effective in reducing substance use in this population. Because of the exciting

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A NEW LOOK AT PSYCHOSIS

Until the discovery of the first antipsychotic drugs in the early 1950s, treatment of psychotic disorders remained a part of the dark ages of medicine. Often institutionalized, restrained and stigmatized, people suffering from these illnesses were without much hope. With the advent of new medications, patients improved, but the side-effects of the drugs could be severe. The negative symptoms [an absence of emotion and lack of motivation] remained.

Only in the past 15 years, with the advent of "atypical" antipsychotic medications, have clinicians, families and patients started to view these illnesses differently. Previously, physicians delayed offering a diagnosis to avoid labeling individuals, especially young people, as mentally ill. Doctors often did not immediately prescribe these powerful and potentially dangerous drugs and they aimed at keeping doses low and of short duration.

The Department of Mental Health's annual training conference titled, "Early Intervention in Psychosis," reviewed evidence that early treatment of psychosis may contribute to shorter illness duration and severity. The September 17-18 conference was sponsored by DMH and its two Research Centers, the Commonwealth Research Center, Harvard Medical School, and the Center for Mental Health Services, University of Massachusetts Medical School. The training conferences provide the Department's state and vendor workforce understanding of current healthcare approaches. Speakers from both centers, as well as consumers, family members and specialists on ethical, legal, gender, adolescent and cultural affairs offer the broadest possible scope of the issues.

Moe Armstrong, Director of Consumer Affairs for Vinfen Corp., a DMH vendor of residential services, described what the start of hallucinations is like for him: "a rushing sound, sleeplessness, then voices and a slide into paranoia." He believes the best intervention is good prevention. Consumers need education on "what we have" and "how to live with our illness."

Hope for the future was expressed by Dr. Ming Tsuang, superintendent and head of the Harvard Department of Psychiatry at the Massachusetts Mental Health Center: "If neuroleptics (antipsychotic medications) have protective effects on the brain for first episode schizophrenic patients, it may be that some day, they, or drugs yet to be developed, along with psychosocial and pharmacological interventions, will prevent the onset of psychosis."

The conference, co-chaired by Dr. Robert Goisman and Raymond Flannery, Jr., of DMH, is one of a series of new initiatives in public managed care. As part of its commitment to training, DMH underwrote the cost of this program, including the continuing medical education credits (CME.)

Childhood Schizophrenia

Interest in childhood schizophrenia is growing due to evidence suggesting that, although rare, schizophrenia may occur in children. Often misdiagnosed as behavior problems or other neurological disorders, early onset schizophrenia benefits from early detection.

Warning Signs of Child Schizophrenia:

- Speech disturbances;
- Inability to distinguish dreams from reality;
- Confused thinking;
- Vivid and bizarre thoughts and ideas;
- Seeing and hearing voices which are not real;
- Extreme moodiness;
- Severe anxiety and fearfulness;
- Behaving like a younger child;
- Ideas that people are "out to get them;"
- Confusion of television with reality; and
- Severe problems making and keeping friends.

National Alliance for Research on Schizophrenia and Depression (NARSAD) newsletter, Fall 1998

How to Succeed in Business ... Consumer-Run Initiatives

by Steve Holochuck

For the past six years, the Department of Mental Health's Office of Consumer and Ex-Patient Relations (OCER) in Central Office has provided grants for projects planned and operated by consumers. These initiatives give recipients the opportunity to highlight their abilities as leaders, collaborators, artists and contributors to community life. The initiatives have embodied positive images of consumers and have served to fight stigma, particularly through media coverage. Grant recipients have enthusiastically testified to the degree to which their work has contributed to recovery and empowerment. Many develop skills and abilities useful in competitive employment.

For the current fiscal year, DMH has awarded $92,250 in grants through OCER to projects across the Commonwealth. A selection committee, predominately made up of members of the Consumer Council, reviews the proposals submitted and makes final selections. Current projects include: A Night at the Wang (multidisciplinary arts project for adolescents), Voices (empowerment theater company), Consumer Legal Education Network (human rights workshops and advocacy), Tunefoolery (musical group), It's About Time (research and education on consumer history in the state), Maxwell's Coffee House (live music for and by consumers and their friends), Dual Recovery Newsletter (publication for persons diagnosed with mental illness and substance abuse), Nutrition Education and Cooking with Rose, and Consumer Warm Line and Caring and Sharing Telephone Line Enterprise (both phone-in help lines for non-crisis peer support). In addition, the Western Mass. Area is supporting 24 projects with $57,000 in funding and the Metro Suburban Area is allocating $76,000 for three projects in FY99.

Integral to the project is the mentoring offered by Community Health and Alternative Opportunity Services, which provides support and technical assistance to all the undertakings supported by OCER. With eventual independence as a major goal, some of the endeavors have gone on to obtain other grants or have become self-sustaining. OCER will announce the next selection cycle this winter.

If you would like to receive the announcement or find out more on the consumer-run initiatives, please call the OCER Information and Referral Line at 1-800-221-0053 (Toll-Free in Massachusetts).

Steve Holochuck is Director of the DMH Office of Consumer and Ex-Patient Relations.

THE COST of DELIVERING MENTAL HEALTH CARE

A survey published by the National Association of Psychiatric Health Systems (NAPHS) presents average salaries for a variety of key positions in organizations providing treatment for psychiatric and addictive disorders. The average national annual salary for a staff psychiatrist is $126,585. The survey looked at differences in salary by the size of organizations and by geographic regions. In New England, the average annual salary for a psychiatrist directing an inpatient unit or program was $125,356, slightly less than the national average.

While most physician groups experienced an increase in income, psychiatrists experienced a decline that now places them at the lowest level of the major specialty groups. What does this say when the Physician's Marketplace Statistics 1997/1998 reports an annual median income of $255,000 for specialists of cardiovascular diseases?

Table **National Full-time Equivalent Base Salaries**

Position Description	(n)	National: Average Annual Salary (Full-time)
Chief Executive Officer (CEO)		
CEO/M.D. (not serving as Medical Director)	9	$197,834
CEO/Medical Director (M.D.)	9	207,498
CEO/Administrator (non M.D.)	72	123,959
Top Financial Executive	69	76,310
Top Alternate Services (non-inpatient) Executive	15	70,426
Top Nursing Executive	76	65,451
Top Medical (M.D.) Director (not CEO)	40	150,890
Staff Psychiatrist (M.D.)	29	126,585
Top Psychology Director (Ph.D.)	24	70,530
Top Social Worker Director (M.S.W.)	63	47,958
Chemical Dependency Program Director for Inpatient	33	54,777
Employee Assistance Program Director	7	46,302

The 1997 NAPHS Salary Survey presents average salaries for a variety of key positions in organiziations providing treatment for psychiatric and addictive disorders. Salary data for all behavioral health positions are presented on a national basis as well as by geographical area and scope of operations defined by revenue.

Source: National Association of Psychiatric Health Systems *1997 Salary Survey.* Used with permission.

Briefly Noted...

RECOGNIZED at the AMERICAN PSYCHIATRY ASSOCIATION's CONVOCATION of FELLOWS: Each year the APA honors individuals who have advanced the field of psychiatry through clinical care, research, public policy or advocacy.

The Solomon Carter Fuller Award, named after one of America's first black psychiatrists: ***Deborah B. Prothrow-Stith, M.D.***, professor of public health practice, Harvard School of Public Health. In her lecture, "Violence Prevention: a Public Health Mandate to Save Our Children," she expressed concern about an attitude prevalent in the U.S., that violence is inevitable, a problem fueled by being defined as a criminal justice issue. Prothrow-Stith praised the Violence Prevention Program at Boston City Hospital and that institution's educational work in the community.

Other awards granted: the APA Award for Research: ***Robert McCarley, M.D.***, professor and chair, Harvard University Department of Psychiatry at Brockton/West Roxbury Veteran's Affairs Medical Center; Wienberg Award for Geriatric Psychiatry: ***David Blau, M.D.***, former president of the Boston Society for Gerontologic Psychiatry; Lilly Psychiatric Research Fellowship: ***Marlene Freeman, M.D.***, Harvard Longwood Psychiatric Residency Program.

OBESITY and the BRAIN: To find a treatment for this very serious condition, researchers are looking not to the abdomen, but to the brain. The brain keeps itself informed on how much energy is available for use and when this energy runs low, the brain activates thoughts of a nice thick steak. "We're beginning to understand the web of chemical signals involved in the body's use of energy," says Cliff Saper of Beth Israel Deaconess Hospital and Harvard Medical School. The most promising fat fighter is a hormone called leptin (from the Greek word meaning thin.) Andrew Greenberg, director of the program and leader of the study reported that in clinical trials in humans, participants receiving leptin injections lost six to seven percent of body weight.

PROMISING NEW MEDICATIONS in DEVELOPMENT: This year, pharmaceutical companies are developing 85 medications to treat psychiatric disorders, from Alzheimer's to depression to addiction. They are investing $4.8 billion to discover and develop medications that act on the central nervous system. New drugs for treating depression and schizophrenia are being researched that could be more effective than currently available medications and may work without the disabling side effects now associated with some antidepressants and antipsychotics.

Free Publications on the Brain From the Dana Press

The Dana Press, publisher for the Charles A. Dana Foundation, produces periodicals, reports, reference works, and books on the promise of brain research. They include:

- **The Brain in the News** (biweekly); reprinted articles from major newspapers.
- **Brain Work: The Neuroscience Newsletter** (bimonthly); lay oriented articles dealing with the brain, its powers and problems.
- **Delivering Results: A Progress Report on Brain Research** (annual) recap of the progress made in all areas of brain research.
- **Brain Connections: Your Source Guide to information on Brain Diseases and Disorders** (annual); reference guide for contacting organizations that deal with specific brain problems.
- **Unlocking the Mysteries of the Brain**; Nine-page pamphlet outlining current brain disorder research methods, findings and their implications.
- **The Charles A. Dana Foundation Annual Report** and **Dana Report**.

To request copies of these publications, write to:
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DMH Employees Honored with Citations

Nineteen Department of Mental Health employees received Commonwealth Citations for Outstanding Performance at a Performance Recognition Awards Dinner, Thursday, October 8, at the Sheraton Boston Hotel. Governor Paul Cellucci delivered the keynote address.

The 19 DMH winners and those from other state agencies helped departments and divisions reach priority objectives. They demonstrated organizational, managerial, or communications skills, exemplary leadership, and helped to make significant improvements in productivity or realize substantial savings in agency operations.

This is the 15th consecutive year of recognizing exceptional state employee performance. It was formerly known as the Pride in Performance (PIP) awards program.

Among the DMH employees receiving this year's Performance Recognition Awards were: (from top, left) Charlotte Pageau-Pierce, Worcester State Hospital; William Ouimet and Luanne Zehelski, Western Mass. Area; Kathleen Duke, Southeastern Area; (second row, from left) Deborah Little, Metro Boston Area; Peter Caesar, Northeast Area; Julia Joy Jennings with mother and award recipient Doreen Jennings, Metro Boston Area; (bottom row, from left) Louis Borges, Jeffrey Silvia, DMH Commissioner Marylou Sudders, Richard Larrabee, James Cleary, and Ron Dailey, Deputy Southeastern Area Director.

(AWAKE) Continued From Page 4

tions and paranoid delusions in her early 20s and was diagnosed with schizophrenia. She experienced no significant response on conventional antipsychotics but did develop severe tardive dyskinesia while taking these medications. She has shown considerable but finite improvement over two-and-one-half years on olanzapine.

Her fantasies of a cure had been raised by optimistic researchers and clinicians as her initial improvement kept her out of hospitals for the duration of her treatment. But, she reminds us, she lost the love of her life during her illness and she is still on disability. She is grateful that she is no longer dominated by psychotic processes, but is unable to reach her "old level." She often asks if new medications are coming out.

Finally, a young woman who repeatedly starts and stops her atypical antipsychotic treatment explains that the weight gain she experiences on clozapine is sufficiently unpleasant to her that she takes breaks from it. Her mental state is strikingly different on clozapine, and she is also able to avoid using drugs when she takes it. "It seems I can only have a mind or a body," she reports.

Sense of Connection

The self, in connection to others, is a second area that is central to our recovering patients. This is the area in which skill deficits are the most apparent. At MMHC, we have an ongoing clozapine support group that serves as a forum where patients further along in their recovery teach those patients who are in an earlier stage of recovery. Pragmatic skill-building groups, coupled with paired role-playing, helps patients with this aspect of recovery. In the individual sessions, attending to the therapeutic relationship as an interpersonal process is also important.

A 52-year-old man with paranoid schizophrenia, who had been hospitalized more than 10 times, had been living a profoundly isolated life while conventional antipsychotics poorly controlled his positive and negative symptoms. He lived marginally in his own apartment and refused offers of group living or day programs. Following a 14-month trial on olanzapine, his grooming improved, as did his ability to describe his affective experiences, and he became romantically involved with a woman at a day treatment center.

After living 20 years without an intimate relationship, he felt overwhelmed with the newfound stresses of this connection. He discussed the pressures of being in this relationship and twice switched back between his old medications and the newer medications. More recently, he chose to move to a living situation that gives him more access to other high-functioning members of the MMHC community. He now has a pet for the first time in his life and cares for it lovingly. He reports pleasure in these connections and says that for now, at least, he is not yet ready for a more intimate relationship.

A 38-year-old woman, who had a diagnosis of schizophrenia with long-standing paranoid symptoms, had been hospitalized more than five times. She talked about her difficulty finding a peer group now that she had become more social:

"I don't have a lot of friends, but my parents are with me. They stood by me through all the illness I had. I want to meet normal people ... [but] I've been with so many mentally ill people that it's hard for me to make up things to talk about. I used to know a lot of people from church, but now I know nobody. I never had my teenage years. That's why I don't seem mature."

The loss of a sense of continuous development or uninterrupted narrative is a common sorrow for these patients. Time spent in the "sick role" with an active illness may limit the development of mutual relationships. The patient describes a nether world of relationships that is neither well nor sick. We know of no magic formula to aid in this process but would rely on her support group, clinician and her own strength to experiment with different kinds of connections, learning from each one.

Sense of Purpose

We observe that people often search for a sense of purpose and spirituality as their symptoms remit to a substantial degree. A large number of them understandably yearn to return to their former hopes of what they had wanted to become, but instead must grieve this loss and attempt to find meaning and purpose in their reconfigured lives. As they work through their grief, rehabilitation and/or occupational training can solidify a sense of purpose and competence in these patients (Arns and Linney, 1993).

A 46-year-old married woman diagnosed with

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schizoaffective disorder more than 25 year ago, who survived more than 10 suicide attempts and a long history of cocaine abuse, talks about how her beliefs have changed over the year since she started taking clozapine:

"Every night in the past when I went to bed, I would ask God to take away my life. Things have changed now that I am better. Now I feel there is a God. There is a divine spark in all of us ... he has his own agenda. My life is only tragic if I am not on clozapine. When I was on the other antipsychotic, my thinking was slowed. I couldn't concentrate on my writing. My purpose in life is to do God's will. He gave me a gift for language and writing. I have to use them to help those still suffering to write about their — our — suffering."

There's little doubt that the growth of therapies for schizophrenia will continue to open complex psychological doors for our patients. Convincing payers that these developmental and existential issues are worthy of payment will become a policy challenge for caregivers.

Research demonstrating the cost-effectiveness of psychotherapeutic efforts for this population (e.g., in terms of improved medication compliance), coupled with data indicating that clozapine is a cost-effective intervention (Meltzer et al., 1993), could help to establish the need for individual psychotherapy, support groups and intensive vocational training for these patients. With or without such data, we believe that this study upholds the notion that the psyche in persons with psychotic disorders warrants psychotherapeutic care. By learning from the people who have managed this transition well, we can better utilize the next wave of pharmacological successes.

(Reprinted with permission from the Psychiatric Times.)

Ken Duckworth, M.D., is the medical director of continuing care services at the Massachusetts Mental Health Center in Boston.

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(DRUGS) Continued From Page 5

preliminary findings, careful prospective studies will begin soon at the Commonwealth Research Center to further characterize the response of such patients to novel agents. If the preliminary findings are confirmed by more rigorous study, it may suggest an important new strategy for the treatment of patients with substance use disorders and schizophrenia.

For further information about the "dual diagnosis" research program at the Commonwealth Research Center, call Dr. Ellen Burgess at 617-734-1300, extension 507.

Dr. Ellen S. Burgess is a research associate at the Commonwealth Research Center and instructor in psychiatry at the Harvard Medical School; Dr. Suzannah V. Zimmet is a research psychiatrist at the Commonwealth Research Center and instructor in psychiatry at the Harvard Medical School; Dr. Alan I. Green is director of the Commonwealth Research Center and associate professor of psychiatry at the Harvard Medical School.

The DMH *Bulletin*

A quarterly publication of the Massachusetts Department of Mental Health, reporting state news and relevant information for clients and their families, mental health professionals, vendors of services, and all citizens interested in the goals and mission of this human service agency.

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The DMH *Bulletin*
25 Staniford St.
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Changing
MINDS

Address Correction Requested

The DMH Bulletin

Massachusetts Department of Mental Health Vol.1 No 16 Winter 1999

From the Commissioner

State extends support line to homeless mentally ill

By Marylou Sudders

Homelessness, grounded in a tangle of reasons unique to every individual on the streets, is receiving heavy attention as the serious national problem it is and has been since the days of the Great Depression, particularly in large cities. The troubling deaths of seven homeless people in Boston since October has moved the focus beyond the need for shelter beds to the equally important support programs that prompt people to come home again.

The Massachusetts Department of Mental Health began addressing the deeper needs of people who are homeless and mentally ill in 1992. That is when a Human Services Research Institute study, commissioned by DMH, estimated that of the total number of homeless individuals in the Commonwealth, approximately 2,000 had severe and persistent mental illness at any point in time. The study indicated that more than half of the homeless people with mental illness were located in Metropolitan Boston. The remaining individuals were scattered throughout the state, primarily in other urban locations.

Following this study, a DMH Special Homeless Initiative was launched with support from the Administration, the Legislature and homeless advocates. The primary goal is to address the cyclical nature of homelessness by creating not only transitional residences, but developing or securing safe, affordable, permanent housing and a full range of appropriate support services designed to help stabilize individuals. Support services range from counseling, case management, education and training to clinical care and first aid.

The initiative is supported by a state appropriation of $19.1 million. As a result, 788 new units of housing exist statewide and 1,422 homeless mentally ill people have been housed from 1992 through the first quarter of the current fiscal year. In addition, 4,886 people have received outreach, clinical and other support services. In Metropolitan Boston alone, 586 units of housing have been developed, 885 homeless mentally ill individuals housed and 2,187 people have received outreach, clinical and other support services.

In addition, through partnerships with community providers, local housing agencies, and city and town governments, $62 million, primarily in federal funding, has been leveraged in rental assistance, support services and capital ("bricks and mortar") costs associated with housing development. The impact of the initiative is even more substantial than these figures reflect. As an indirect result, it identifies individuals at risk — thus preventing future homeless situations.

The initiative also has significantly increased the DMH's capacity to provide outreach programs, which are key to preventing homelessness. In the Boston area, a Homeless Outreach Team engages homeless mentally ill individuals who live on the streets and in emergency shelters throughout Boston and Cambridge and provides initial support and service referrals. All referrals for DMH transitional housing in Boston are funneled through the Homeless Outreach Team.

The DMH inpatient discharge policy prohibits discharging a client from a state-run facility directly to a shelter or the streets and endorses exhausting every avenue to find appropriate housing. This policy will be extended to hospitals with psychiatric units that are licensed by the Department.

Another aspect of the overall initiative is geared towards serving homeless individuals with co-occurring mental illness and substance disorders. In conjunction with the Massachusetts Department of Public Health, a supportive housing grant was garnered from the federal Housing and

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"PSYCHOECONOMICS" ... aka, STIGMA

Psychoeconomics, a term used to illustrate the economic benefit of new psychiatric medications, means that a drug must not only improve life for an individual suffering from serious mental illness, but provide an economic benefit. Appalled that researchers would accept such a concept, Dr. Paul J. Fink, professor of psychiatry at Temple University, says, "I don't think cancer researchers will ever be asked to justify their work using economic criteria."

Relief of pain, suffering and symptoms motivate scientists in their search for better and more effective medication treatments along with the hope that long-term improvement will return patients to the work force. Psychoeconomics puts the cart before the horse.

Brain research now races to reach goals thought impossible only a decade ago: relief from the suffering of depression, psychoses, dementia and many other diseases of the brain. New psychosocial and rehabilitation programs flow from this research, with renewed hope for patients and their families. Psychoeconomics makes no more sense than cardioeconomics would make for heart research.

"CHANGING MINDS" GOES GLOBAL

When Norwegian Prime Minister Bondevik returned from a month's sick leave, he held a press conference to let the world know he suffered from depression, an illness which he said he hoped "to demystify." Opinion polls showed 85% of Norwegians supported his decision to disclose his diagnosis of depression. In England, the Royal College of Psychiatrists is hoping people there will become as enlightened. The college has launched "Changing Minds," a five-year campaign to "reduce the stigma and discrimination against people with mental illness." Like the Massachusetts DMH campaign, the Royal College campaign has produced educational materials "to make you think differently about these illnesses."

PEOPLE for PROGRESS

Still together, still challenging the stigma of mental illness, "People for Progress" is a group founded and initially funded by the Department of Mental Health. Now in its own offices in Framingham, it is launching a year-long education program. It is already booked for presentations to Rotarians, with plans to reach schools, lawmakers and the media. For more information, call Iris Carroll at (508) 879-3230.

WHAT DOES STIGMA FEEL LIKE?

To convey a sense of the unreality, fears and loneliness experienced by persons with mental illness, Dr. Karl Menninger put it this way:

When a trout rising to a fly gets hooked on a line and finds himself unable to swim about freely, he begins a fight which results in struggles and splashes and sometimes an escape. Often, of course, the situation is too tough for him.

In the same way the human struggles with his environment and with the hooks that catch him. Sometimes he masters his difficulties; sometimes they are too much for him. His struggles are all the world sees and it usually misunderstands them.

It is hard for a free fish to understand what is happening to a hooked one.

Karl A. Menninger, M.D., The Human Mind.

MEDICATIONS and MORE for TREATMENT of SCHIZOPHRENIA at the FREEDOM TRAIL CLINIC

Cognitive-Behavioral Treatment for Psychotic Symptoms

By Virginia Mays, Ph.D.

Although medications such as the new atypical neuroleptics are very effective in the treatment of schizophrenia, they often do not ameliorate symptoms completely: some people diagnosed with schizophrenia will continue with persistent medication-resistant psychotic symptoms. This means that most clients find these medications effective for improving their ability to cope with their illness in general, but some continue to hear voices and experience delusional beliefs. Because auditory hallucinations and delusions are distressing, these symptoms may interfere with an individual's ability to function effectively.

Cognitive-behavioral therapy (CBT) is often helpful in treating these medication-resistant psychotic symptoms. These techniques have been found to be effective in the treatment of many other disorders (depression and anxiety, for example). Several innovative research programs worldwide are applying CBT techniques to the unique problems of schizophrenia. The theory behind this approach is that psychiatric disabilities are often maintained and exacerbated by dysfunctional thought patterns and ineffective behaviors.

The goal of CBT therapy for psychotic symptoms, therefore, is to help people develop more productive ways of reacting to their symptoms. CBT therapists commonly work with these clients to assess and then alter the ways they interpret and think about their hallucinations and delusions. Changing thoughts and behaviors related to psychotic symptoms often decreases the impact these symptoms have on an individual's life.

For example, many patients are confused about the source of these thoughts. Individuals will often vacillate between believing that their psychotic symptoms are directly related to the illness or attempt to explain the symptoms through delusional beliefs. A person may initially acknowledge that voices heard are not real and stem from the imagination and problematic brain chemistry. An hour later, the individual may speculate that perhaps the voices heard come from a computer chip that has been implanted in the brain by the CIA.

A CBT therapist working with such a client would likely empathize with the client's uncertainty and work to explore the situation in greater detail. The therapist also might help the client develop ways to "test" which explanation is more likely by asking whether others hear the voices or by reviewing the evidence for and against the possibility that a government agency is involved. Modifying delusional beliefs and hallucinations is one way to approach the treatment of these symptoms, but cognitive strategies may be facilitated by behavioral strategies as well.

One behavioral intervention found useful, for example, involves identifying the pattern that occurs in a client's life prior to hearing voices. Research has demonstrated that, for some, auditory hallucinations are exacerbated by stressful situations. If this appears to be true for a particular client, the individual might work with a CBT therapist to develop ways to better cope with particular stress-inducing situations. Other behavioral methods found effective for some clients are: wearing an earplug in one ear, learning methods to consciously distract self from the voices, or focusing upon the form the voices take rather than the content.

Although research into cognitive-behavioral techniques as they apply to schizophrenia is relatively new, the Psychotic Disorders Team at the Freedom Trail Clinic is conducting several potential ground-breaking studies over the next few years. This clinic, which is affiliated with both Harvard University Medical School and Massachusetts General Hospital, is already engaged in research in identifying the physiological bases of schizophrenia and examining the efficacy of medication for symptoms of schizophrenia. It is this type of research that leads to the development of more effective treatments for individuals who live with schizophrenia.

Several studies will be beginning soon, including one that assesses group cognitive-behavior therapy for psychotic symptoms and another that assesses qualities of auditory hallucinations as they relate to personality, mood, and other variables.

If you are interested in being part of a study or a clinician interested in additional information about CBT for schizophrenia, feel free to contact Virginia Mays, Ph.D., at the Freedom Trail Clinic: (617) 912-7891.

Virginia Mays, Ph.D., is a Fellow at Harvard Medical School and Massachusetts General Hospital, a research and clinical psychologist at the Freedom Trail Clinic at the Erich Lindemann Mental Health Center in Boston.

Two Research Centers of Excellence....

The Center for Psychosocial and Forensic Services at the University of Massachusetts Medical Center in Worcester and The Commonwealth Research Center at the Massachusetts Mental Health Center in Boston are funded by DMH. They bring together some of the best minds and talent in Massachusetts to advance treatment and rehabilitation methods for chronic, persistent and severely psychiatrically ill patients. The Center at the University of Massachusetts Medical Center concentrates on Behavioral and Forensic Services. The Commonwealth Research Center focuses on Clinical Neuroscience and Neuropharmacology. This issue of the Bulletin presents an article from UMASS on transitional employment .

JOB TRAINING SUCCESSFUL AS PART of POP
Transitional Employment Builds Self-Confidence

by Jonathan Clayfield

For the past 18 months, the Center for Mental Health Services Research at the University of Massachusetts Medical School has been employing and training members from Employment Options and Genesis Club psychosocial rehabilitation programs, to be research assistants as part of the Parenting Options Project (POP). These transitional employment (TE) placements typically last from six to nine months, and have proven a great success so far within the three-year, NIDRR (National Institute on Disability and Rehabilitation Research) and DMH-funded project. Two former research assistants have gone on to supported employment (SE) positions in other research projects at the Center, and one has secured an independent employment position within the University of Massachusetts Medical Center.

In all, eleven members have trained and participated as temporary employment research assistants in the parenting project to date, with many more expected before the project is completed. The research assistants are trained to do a number of different tasks as part of the project, some of which include: word processing, database development, database entry, statistical analysis, writing, participating in project work groups and meetings, performing resource searches on the Internet, performing literature searches using the medical center's MedLines database, and presenting project data at workshops and conferences.

In addition to providing members from Employment Options and Genesis an opportunity to learn research-related skills, the project also has received feedback from past and current temporary employment research assistants on how this experience has affected them personally. Many such research assistants have felt intimidated by the position initially, doubting their ability to perform such research-related tasks. However, nearly all have reported an overall increase in their feelings of self-esteem and self-confidence through their many accomplishments on the project. Larry Stier of Employment Options, a temporary research assistant in the POP project and a current supported employment research assistant on another project at the center, stated that, "The TE research assistant position is unique in that you work at your own skill level, and days that you may not be up to par you can work at that level. All the tasks given us are accomplished. One person's strength may be another person's weakness but, between us, we get the job done. We also add our input to the POP project using our individual experiences."

The parenting project staff has noticed the profound effect the position has had on many past and current research assistants as well. They look forward to the occasional opportunity to remind a temporary research assistant who, matter-of-factly uses the computer for tasks involving word processing, data entry and the Internet, that she had initially predicted she would never be able to learn such skills. Of course, the hardest part of the temporary research assistant position expressed by all of the parenting project staff is that these jobs are "transitional," which means facing the difficult task of eventually having to say good-bye. Yet, many of the research assistants maintain an optimistic outlook about exploring other employment opportunities upon leaving the project. As one former transitional research assistant put it, "I don't know what the future holds for me, but I am sure that all that I do and have learned will greatly help me in any future endeavors." Another former research assistant, Del Kimball of Employment Options, added, "I and the other research assistants felt that UMass had gone the extra mile in helping members get back to work and, at the same time, helped us feel comfort-

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Briefly Noted...

HEALTHY PEOPLE 2010, a simple idea that calls for a health agenda for the nation originated in the 1979 surgeon general's report on health promotion and disease prevention, entitled, "Healthy People." It sought "to encourage a second public health revolution in the history of the United States." The 1979 report called for the dramatic recasting of national health strategy to emphasize prevention of disease and promoted the notion that establishing national goals and monitoring progress would motivate action to improve the nation's health.

Healthy People is the federal government's once a decade prioritization of positive changes in health care, reductions of risk factors and improved provision of services. Healthy People 2000 has been the driving force for many health care initiatives, research funds and new measures and standards of care.

Development of national health objectives has already begun. The 2010 draft objectives are now posted on the Internet for public comment; it is an opportunity to influence national research and program priorities. The 2010 objectives have two main goals:
Increase quality and years of healthy life; and
Eliminate health disparities.

These goals include four broad categories:
Promote healthy behaviors;
Promote healthy and safe communities;
Improve systems for personal and public health; and
Prevent and reduce diseases and disorders.

Public involvement will continue through the next 18 months. Healthy People 2010 web site: http://web.health.gov/healthypeople. Or call for Laying the Foundation for Healthy People 2010, Office of Disease Prevention and Health Promotion (202) 205-8583.

FISH AS BRAIN FOOD: Was grandma right after all? At an international conference sponsored by the National Institutes of Health, scientists reported that evidence suggests higher consumption of essential fatty acids found in fish and fish oils may reduce symptoms in a variety of psychiatric illnesses, including schizophrenia, bipolar disorders and depression. One study conducted by Andrew Stoll, M.D., of Harvard Medical School found patients with manic depression responded favorably to daily supplements of omega-3 fish oil. Results of global studies indicate that countries where large quantities of fish are eaten have lower rates of depression. One explanation may be that the brain's membranes where neurological signaling takes place have a high proportion of fatty acids derived entirely from diet. Dr. Stoll calls the implications "very exciting."

FAMILY CAREGIVERS SUPPORTED

The American Medical Association recently turned its attention to important mental health issues when its House of Delegates adopted a resolution affirming the importance of educating physicians about the role of family caregivers, including those providing care for mentally ill relatives. It encouraged medical schools and residency programs to prepare doctors to assess and manage caregiver stress and to support research that identifies the types of education and support services needed by those who care for patients with dementia, addiction and psychiatric disorders.

Since 1994, the Department of Mental Health has supported "Family to Family," an education program offered by NAMI instructors (National Alliance for the Mentally Ill) who have a family member with a mental illness. Now taught in 36 states and two provinces in Canada, the course boasts more than 35,000 family member graduates. Massachusetts has 45 trained teachers and 415 graduates. Spring courses will be starting on the Cape, in Western Massachusetts, and in the Taunton, Bedford and Fitchburg areas. A fall class is already scheduled in Lexington. Bilingual co-teachers would make it possible for the new Spanish translation of the course to be offered this fall.

Two more curricula are in the works, one for professionals and one for consumers. Professionals and consumers interested in teaching or taking the Family to Family courses tailored for them should contact Lois Pulliam at (781) 275-0090 for a listing of upcoming classes.

DMH Employees Honored with Citations

Nineteen Department of Mental Health employees received Commonwealth Citations for Outstanding Performance at a Performance Recognition Awards Dinner, at the Sheraton Boston Hotel. Governor Paul Cellucci delivered the keynote address.

The 19 DMH winners and those from other state agencies helped departments and divisions reach priority objectives. The recipients demonstrated organizational, managerial, or communications skills, exemplary leadership, and helped to make significant improvements in productivity or realize substantial savings in agency operations.

The event was the 15th consecutive year of recognizing exceptional state employee performance. It was formerly known as the Pride in Performance (PIP) awards program.

Among the DMH employees receiving Performance Recognition Awards were: (from left) Patsy Taucer, Central Mass. Area; Irene Princiotta and Diane Donohue, Metro Suburban Area; Leandra LaFrazia, Central Office.

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Urban Development agency. A total of $2.4 million is allocated over the next three years for an aggressive treatment and relapse program. Five pilot projects, each with the capacity to house and support 12 dually diagnosed individuals, have been developed across the state. The goal of the program is to assist homeless individuals and their families with rehabilitation and recovery, achieving independence and securing permanent housing.

Employment is instrumental to successful reintegration of the homeless mentally ill client into the community. In partnership with the Division of Employment and Training, employment programs have been developed to assist clients in finding and retaining jobs in competitive, independent, employment settings. Employment Connections began serving clients in the Metropolitan Boston area in Fiscal Year 1996. The program was expanded statewide a year later. Participants are employed in a myriad of occupations from personal care attendants, caterers, customer service representatives, administrative assistants and medical transcribers to computer repair technicians, landscapers, sales representatives and assistant managers. Employment Connections provided services to 246 formerly homeless mentally ill individuals during the past fiscal year.

The Department of Mental Health continues to work closely with the Massachusetts Housing and Shelter Alliance to bring a heightened sensitivity to the needs of homeless mentally ill individuals. By providing outreach, developing transitional residences and permanent housing, offering education and training, treatment and support services, our objective is to eradicate homelessness. For now, we must keep providing short and longer term solutions.

Working Together for Consumer Empowerment and Recovery

By Deborah Bridge

Massachusetts People/Patients Organized for Wellness, Empowerment and Rights, better known as M-POWER, recently received three national leadership development grants to give mental health consumers/psychiatric survivors/ex-patients (csx's*) new and important opportunities. M-POWER is a csx-run organization with a central office in Boston. Leadership planning sessions will shape a project where csx's become increasingly effective in helping Massachusetts decision-makers design and carry out quality, recovery-oriented services.

The federal government's Center for Mental Health Services (CMHS) supports two of the projects, making M-POWER one of two csx-run organizations in the nation to receive an exemplary practice grant this year. The Campaign for Human Development, a Washington D.C.- based Catholic charitable organization, will help the organization develop independent funding.

M-POWER coordinated the process by which csx leaders from across the state clarified the goals of these projects. The Negotiating Team, a group of leaders drawn especially from the Massachusetts Coalition of Consumer/Survivor Organizations, played a central role in this process. It received active support from Department of Mental Health Commissioner Marylou Sudders, the DMH Office of Consumer and Ex-Patient Relations and other DMH staff. In addition, key administrators at the Division of Medical Assistance and the Massachusetts Behavioral Health Partnership supported the effort.

The statewide leadership projects include four teams, each with special training and planning roles. The first planning team will work on developing a leadership academy modeled after a nationally respected training project. Planning team members will participate in three 2 and-a-half day retreats where they will learn directly from the Idaho Leadership Academy and adapt the training experience to Massachusetts. Most importantly, the planning team will try to develop consensus with decision-makers and other interested parties on how to make the academy most effective.

The cultural competence team will attend a five-day training with the National Coalition Building Institute in Washington, D.C. This second team will carry out trainings in prejudice reduction for other Massachusetts csx leaders.

In Western Massachusetts, M-POWER will offer a third team experience with nationally known csx advocate Yvette Sangster training leaders in 14 day-long workshops. In addition to learning advocacy-related information and skills, participants will focus heavily on public presentations. The class members will videotape and critique each other to help participants increase their ability to effectively communicate.

The Organizing and Leadership Training Center will help leaders learn how to generate resources independently of grants. Resources for a community group include such possibilities as donations, people with special skills or interests, and collaboration that generates growth.

Finally, the network building project will bring all of these teams together for a series of one-day meetings. Participants will gather to envision and seed a network through which csx's can regularly share information, teach each other skills, and develop closer connections.

M-POWER invites diverse and inclusive participation in these activities. The group seeks involvement of csx's who sit on DMH Statewide, Area and Site Boards and committees along with those who may consider taking such leadership roles in the future. Consumers who are advocates, leaders, and/or work in mental health are invited. All consumer/survivor/ex-patients are needed to contribute their vision to this project.

(* "Csx" is an inclusive term to acknowledge people who understand their experiences in the mental health system in diverse ways and nonetheless can come together to work productively.)

Deborah Bridge is the Coordinator of M-POWER. People interested in the project, including positions as paid staff and stipended volunteers, should contact M-POWER at (617) 464-1400 or info@m-power.org.

CASE MANAGED CLIENTS IN THE FORENSIC SYSTEM

Abstract by William Fisher, Ph.D.

The involvement of individuals with severe mental illness in the criminal justice system has long been a concern of policymakers and mental health advocates. This involvement has been assessed at a number of points in the pathways between these systems.

This paper examines involvement in the forensic mental health system, a less well studied feature of the overlap between these systems. Specifically, it looks at the extent to which severely mentally ill, case managed, Massachusetts Department of Mental Health clients are seen in the state's forensic mental health court clinics for evaluation of competency to stand trial for criminal offenses. An analysis of merged data from both systems showed that fewer than 2% of the case managed population was referred to court clinics for evaluation of competency to stand trial during a 12-month period, but that these 2% represented nearly one-fifth of court clinic evaluees seen in that year.

The likelihood of this involvement was higher for males, African-Americans and for persons with a history of substance abuse, and also was associated with lower use of community services and higher levels of hospitalization.

The case managed group had been charged with fewer serious violent crimes than were forensic evaluees not in the case management system. In addition, non-case managed evaluees were more likely to be non-white, male and uninsured than were case managed evaluees, and accounted for a larger percentage of the charges involving serious violent crimes observed in the court clinic population.

These data indicate that demographic characteristics, undesirable service use patterns, residential instability and lack of insurance are potential risk factors for forensic and, by inference, criminal justice system involvement among people with mental illness.

For a copy of the complete study, contact William H. Fisher, Ph.D, Associate Professor, University of Massachusetts Medical Center, at (508)-856-8715.

(UMASS) Continued from Page 4

able and welcome. I felt it was a great learning experience from A-1 people at UMass."

The UMMS Center for Mental Health Services Research was recently nominated by Employment Options to receive an "Outstanding Employer Award" at the Massachusetts Clubhouse Coalition Employer Awards ceremony at the statehouse. The award recognized the Center for providing valuable employment opportunities for the members of Employment Options. For more information about our transitional employment research assistant training program or about POP, please call Jonathan Clayfield at (508)-856-8721.

Jonathan Clayfield is Project Coordinator of The Parenting Options Project at the University of Massachusetts Medical Center in Worcester.

The DMH *Bulletin*

A quarterly publication of the Massachusetts Department of Mental Health, reporting state news and relevant information for clients and their families, mental health professionals, vendors of services, and all citizens interested in the goals and mission of this human service agency.

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WHAT'S HAPPENING?

April Debut of National Alcohol Screening Day

The first National Alcohol Screening Day is scheduled for April 8, 1999. Modeled after National Depression Screening Day, it will address the full range of drinking behavior, from risky drinking to alcohol dependence.

Screenings will be offered through alcohol treatment facilities, hospitals and college counseling centers. Participants will hear an educational presentation about alcohol, take a written screening test, review the test results with a clinician and receive a referral when appropriate. The screenings are free and anonymous.

Information about the locations of screening sites is available after March 15, by calling 1-800-405-9200.

SAVE THESE DATES

The Northeast Area of the Department of Mental Health
and
Express Yourself
present
"OCEANA" A NIGHT AT THE WANG V
at 6:30 p.m., MONDAY, MAY 10, 1999

RECOVERY and REHABILITATION

A conference for people experiencing alcohol/substance abuse and mental illness sponsored by the Center for Psychiatric Rehabilitation, Sargent College at Boston University, the Massachusetts Department of Mental Health and the AMI/DMH Curriculum and Training Committee.

June 15, 1999
8:15-5
Boston University
775 Commonwealth Ave. Boston, MA
Call: (617)-353-3549

HAVE A QUESTION? NEED A REFERRAL? CALL OCER at 1-800-221-0053

The Office of Consumer & Ex-Patient Relations (OCER) offers a toll-free information and referral line for the public during regular business hours. Pamela Mason, the information & referral specialist, answers questions about such mental health issues as human rights, housing, access to services, and groups for empowerment and recovery. Her experience as a consumer/survivor lends a unique sense of understanding and sensitivity to the needs of callers and knowledge of a broad spectrum of resources. All calls are confidential.

NEW JOB FOR MAN'S BEST FRIEND

When social worker Kris Clasby was a student, part of her training included working with children and adolescents in a group home setting. Sometimes on "overnights," she would bring along her dog. When she did, the agitated child grew calm. A shy, withdrawn child began talking and the tenor of the entire house took on a friendlier tone. Occasionally, a confused and lonely newcomer settled down for the night with the dog by his bed.

Today, a black Labrador named Dancer, a specially trained therapy dog, works with Clasby as a valuable member of the clinical staff at the South Shore Mental Health Center. Dancer was trained by the National Education for Assistive Dog Services (NEADS) in Princeton. It is a non-profit organization which began a Hearing Ear Dog Program in 1976. NEADS later expanded to training service dogs for people with physical disabilities and welcomed the challenge Kris Clasby presented when she asked if they could train a dog to assist in psychotherapy.

Training a service dog takes two years and costs about $6,000. The dogs, some rescued from animal shelters, spend their first 18 months in the foster parent program, living with people who have agreed to house and care for a NEADS puppy until it is ready for service training. The dog then joins the staff in Princeton to learn special skills, such as turning on light switches, fetching and carrying, and, in the case of therapy dogs, learning to offer a paw, put his head on a child's lap, even "high-five" a reluctant teenager. The dog and its new owner spend the last two weeks together on the grounds of the training campus, getting aquatinted and becoming a team.

Often anxious and fearful entering counseling, many children discover Dancer's presence as a welcome ice-breaker. Patting and talking to Dancer offers an easy way to get started. Hugging Dancer provides a non-threatening affectionate experience for a neglected or abused child. A picture of Dancer's mother, a black Labrador named Holly, hangs in Clasby's office, prompting many conversations about troubling family concerns. "Children who have been placed in foster care or whose parents are divorcing may ask whether Dancer misses her mother, helping a child explore and better address issues around separation," says Clasby.

Since Dancer arrived six years ago at South Shore Mental Health Center, two more therapy dogs have joined her, both black Labradors. Bruin has accompanied clinician Karen Kaufman for more than year; Wylie began this winter helping Cathy O'Brien of the Trauma Recovery Team.

Early indication of the potential of animal assisted therapy (AAT) was reported by Boris Levinson, M.D., a Canadian child psychiatrist who included his dog in therapy sessions (1962). He observed that the dog served as a communication link, provided the child with a sense of security, and quickened the therapy process. AAT worked especially well with children who were non-verbal, autistic, withdrawn, even psychotic, by strengthening their contact with reality.

More recent studies confirm the ability of animals to demonstrate acceptance by allowing themselves to be petted, to reduce the threat of the therapy session by their presence and to serve as a distraction while talking about painful material. Further research will increase understanding of the human to animal interaction and it benefits. Meanwhile at the South Shore Mental Health Center, Dancer, Bruin and Wylie are making children's lives a little brighter and their owners' work easier and more effective.

Northeast Area Kicks off Legislative Breakfasts

The Department of Mental Health's Northeast Area recently held its annual legislative breakfast to thank legislators and advocates for their support and outline its legislative agenda for this session.

The Northeast region receives $7,201 per client, the lowest of any DMH region. But the gap between the least and most financed areas is diminishing. Commissioner Marylou Sudders talked about the financing gap in the Northeast at the State House event. "Historically, the Northeast Area has less resources per capita than the rest of the commonwealth ... We have narrowed the gap by almost $770 per person since FY1996, but we still have work to do," she said.

The Department also plans to fight housing and employment discrimination and provide greater access to care and treatment for adults. DMH will continue to push mental health insurance parity, which would re-

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SOMETHING OLD ... SOMETHING NEW

It has been 50 years and counting since scientists found the connection between depression and the brain's neurotransmitters. Although new medications revolutionized treatment for this disorder, approximately 15% of the 5 -7 million Americans who suffer from depression do not respond to the drugs now available. Help may be at hand.

A skin patch may be able to stick it to depression, using an MAO inhibitor which was developed in the 1950s. This medication carried such strict dietary restrictions that its use was limited. With the new delivery system, negative interactions with food that often led to hypertension and stroke are eliminated.

Dr. Alexander Bodkin, Director of McLean Hospital's Clinical Research Department, calls the patch-delivered monoamine oxidase inhibitor a "powerful treatment of the most common psychiatric disorder in the world, resurrecting the first family of antidepressants ever introduced — one that has never been surpassed in efficacy."

Discovered in 1931, Substance P has been called a neurotransmitter looking for a disease. "P" stands for powder, which is the form it takes, but it has come to stand for pain, because Substance P is found in the pain pathways along the spinal cord. In clinical trials it has not been successful in controlling pain, but researchers noticed that it reduced anxiety and depression in more than half the patients who took it.

Science proceeds slowly, building on the old while seeking new and more effective therapies. Some of the old, combined with the new, may produce very different treatments for depression.

Annual Cost of Depression in the United States:

About $43 billion

Treatment and rehabilitation:
$12 billion

Absenteesim and lost productivity in the workplace:
$23 billion

Loss of earnings due to depression-induced suicide:
$7 billion

Annual economic cost of depression in 1995:
$6,000 per depressed worker

Estimated cost that employers direclty bear annually:
More than $4,200 per depressed worker or $250 per employee

Costs to American businesses of alcohol and drug use:
Approximately $102 billion every year in lost productivity, accidents, employee turnover, and related problems

(BREAKFAST) Cont'd From Previous Page

quire insurers to cover mental illness in the same way as other illnesses when it comes time to pay the bill. The parity bill passed in both legislative branches last year, but the session ended before a compromise could be reached. "There is no greater form of discrimination than the lack of insurance coverage for the treatment of mental illnesses. The time has come to join 19 other states, including all other New England states, to provide parity insurance coverage," said Sudders.

Participating were, from left: Senator Frederick Berry, Commissioner Sudders, Moe Armstrong of Vinfen Corporation, Senator Richard Tisei, and Senator Robert Travaglini.

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The DMH *Bulletin*
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THE DMH Bulletin

Massachusetts Department of Mental Health Vol.1 No 17 Spring/Summer 1999

From the Commissioner

Illness Binds Mother, Daughter Amid Neighborhood Indifference

By Marylou Sudders

This is a true story about a mom, her teenage daughter, and an illness that drew them closer while setting them apart from neighbors. Names aren't important; the message is. It's a tale about a mom and her bout with cancer and her daughter's first episode of mental illness. Neighbors rallied behind mom, visiting her in the hospital, sending flowers and bringing casseroles to her home.

When her daughter became ill and was admitted to a different unit in the same hospital, neighbors responded differently. No flowers, no casseroles, no visitors to the house or to her daughter's hospital room. No mention of her illness. Not a word. Mom felt isolated and disconnected from her neighbors, her community.

Had the teenager been suffering from leukemia, the call would have gone far and wide for bone marrow donors. The search for a suitable match would have commanded public attention. A young girl with a life threatening condition needs help.

Look closely. Mom's daughter has a life threatening condition. That's what mental illness is. It shatters life's dreams and aspirations. Yet people don't react in the same way. Heads turn away. People don't talk about it; few show they care.

Millions of Americans have mental illness. One in every four families is affected. One in 10 children suffers from a diagnosable mental, emotional or behavioral disorder. Nearly 9% of youths between the ages of 9 and 17 are seriously emotionally disturbed; 5 million children 18 or under aren't having their illness treated.

However, treatment for kids with serious mental illness works. New approaches to helping children recover from trauma are succeeding. Advanced medications and therapy are working. New ways to interact with families, especially taking into account cultural diversity, are at hand.

> ***"New approaches to helping children recover from trauma are succeeding. Advanced medications and therapy are working. New ways to interact with families, especially taking into account cultural diversity, are at hand."***

In Boston, where the Department of Mental Health purchases more than $3 million in mental health services for children in public schools, innovative programs are making a difference. A 20% reduction in the juvenile crime rate and 10 consecutive months without a youth killed with a gun or knife didn't occur without interventions. Through the Safe Neighborhood Initiative, a collaborative approach of the Suffolk County District Attorney's office and the City of Boston, young people, some street gang members, found common ground and resolved differences, sometimes through the use of peer mediation counselors.

Child serving public agencies are developing ways to make mental health services more accessible to troubled children and families. For example, the statewide interagency Collaborative Assessment Program enables youth to remain

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Inside This Issue

"Changing Minds" Takes Time ... Says Rosalynn Carter, Former First Lady

For more than 20 years, Rosalynn Carter has challenged the stigma and discrimination that confronts people with mental illness. In her recent book, "Helping Someone With Mental Illness," she writes, "Those who suffer (from mental illness) cannot escape the consequences of stigma. They are reflected in our laws - - zoning laws, insurance laws, discriminatory Medicaid and Medicare rules and housing regulations - - and in funding for research and treatment of mental illness. I have always believed that if insurance coverage made no distinction among illnesses, a lot of the stigma would fade away. The fear and misunderstanding of mental illnesses are deeply ingrained in our society, and changing attitudes takes time."

Dr. Julius B. Richmond, professor of health policy at Harvard Medical School, says that this book "... shows us how understanding of mental illness will lead to improved care and how to combat the stigma long associated with mental illness. This book should be widely read to move us toward a more informed, compassionate society." "Helping Someone With Mental Illness" is now available in paperback and Rosalynn Carter has been on a promotional tour speaking about mental illness.

Rosalynn Carter

The Carter Mental Health Center in Atlanta has initiated several antistigma projects; a fellowship for journalists to study selected topics regarding mental health issues and an antistigma task force, made up of people representing business, education, health care, the media and the religious community; "The Conversation at the Carter Center" program developed into a video that has been shown on PBS and is available from the DMH Public Affairs office. In support of the Massachusetts Changing Minds campaign, the Center has donated several additional copies of the "Conversation" video to the DMH Video Library. Call 617-626-8157.

Mrs. Carter made a public stop May 19 as a fund-raiser for the Genesis clubhouse in Worcester. Genesis is one of 30 clubhouses in the state that provide social and vocational opportunities to the mentally ill.

WHAT CAN YOU DO ABOUT STIGMA?

Be alert to the misuse of inaccurate language:

- Slang words like "nuts," "wacko," "psycho," and "lunatic" are dehumanizing.
- "Schizophrenia," "manic-depression," "psychosis," and "insane" are clinical and legal terms. It is incorrect to call the government "schizophrenic" or to dub behavior "psychotic."
- Labels such as "loony bin," "nuthouse," and "funny farm" are humiliating.
- Depersonalizing people by referring to "schizophrenics" instead of "persons with schizophrenia."

SPREAD THE WORD

Writers, newspaper editors, TV and radio producers and especially advertisers welcome feedback from readers, listeners, viewers and consumers. Help raise awareness about mental illness.

This is what Bill Littlefield, host of "Only A Game," WBUR 90.9FM, wrote to Joan Kerzner, Director of Policy Development, Department of Mental Health:

> *Dear Ms. Kerzner:*
>
> *Thank you for your letter.*
>
> *I'm glad you enjoy "Only A Game," and I appreciate your taking the time to write. I'll keep in mind your observation about my use of the word "psycho." It was certainly not my intention to offend anyone.*

The next time YOU hear stigmatizing language, seize the opportunity to bring understanding to a topic that is widely misunderstood. Want some help with how to do that? Request the pamphlet, "Mental Illness: Information for Writers." Public Affairs 617-626-8157.

(KIDS) Cont'd From Page 3

at or return home through rapid assessments, providing what is needed for a family to stay together, and parental coaches who mentor those new to the public mental health system. Three hundred emotionally disturbed youngsters a year are served.

DMH-funded networks of parents across the Commonwealth provide dozens of regular opportunities for guidance and support in managing their children, navigating the intricacies of insurance and public agency responsibilities, learning more about their child's disability and available treatment options.

There are still miles to travel, however. Latest national figures show 52% of children with serious emotional disturbances never complete high school. Fifteen years ago, adolescents needing psychiatric hospitalization had limited options; 1,300 kids a year entered state institutions because there were few inpatient services available in community and private hospitals for public sector youth.

There are different challenges today. Dozens of hospitals across Massachusetts treat these youth, yet beds are too often unavailable. A citizen's advisory committee earlier this year identified issues facing the children's mental health system. The panel's major concern was the shift in the severity of mental illness affecting all levels of care for children. Pressure to decrease utilization of acute hospitalization in a managed health care environment has resulted in this progressive shift. Each level of care below acute hospitalization is treating more children whose level of disturbance would formerly have been treated in more restrictive settings.

On the community service side, the panel found that demand far outweighed the capacity of agencies to adequately provide services to children with serious emotional disturbance. Moreover, these programs have been adversely affected by the shift in severity. Programs established to serve a stable population now provide services to children with multiple medical, behavioral and societal problems.

The state's child-serving agencies are working to find a remedy. Treating mental illness as an illness would help. A move in the legislature requiring insurers to do so would mitigate the dilemma of hospital stays tied to insurance caps.

In a child's life, everyone is accountable. With children suffering from serious mental illness, the collective efforts of state policymakers, parents, teachers, administrators and clinicians must be marshalled to ensure that youngsters receive the best possible care leading to recovery. Society should demand it.

INITIATIVES UNVEILED AT WHITE HOUSE CONFERENCE

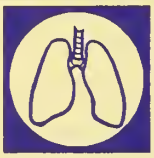
The first White House Conference on Mental Health was the setting and the Clinton administration used it to unveil several initiatives designed to change the way society looks at the illness. They included:

- The National Institute of Mental Health launch of a $7.3 million study on the nature of mental illness and its treatment to help guide strategy and policy;
- A five-year, $10 million pilot program to treat mental illness in people on Social Security disability so they can return to work;
- The Administration on Aging plan to kick off an out reach initiative to educate the elderly and their healthcare professionals about mental illness;
- The U.S. Department of Housing and Urban Development (HUD) unveiling of more "Safe Havens" shelters where homeless people with mental illness can stay and receive food, clothing and take showers;
- HUD launching of a series of three televised awareness and training sessions led by Secretary Andrew Cuomo to help fight housing discrimination against people with mental illness;
- The Department of Justice's Office and the Center for Mental Health Services project to ensure that federal response to crises such as terrorist acts or mass shootings include a strong mental health component, as well as strategies to address the mental health needs of crime victims;
- A Department of Defense plan to combat stress in the military;
- Five-year, $5 million campaign directed to the mental health needs of children;
- The Departments of Interior, Justice, Education and HHS allocation at least $5 million to 10 native American communities to address the mental health needs of youth;
- The president's national school safety training program for teachers and personnel. The National Education Association, with the donation of satellite dishes from the Littleton, Colorado, satellite company, EchoStar, will provide to 1,000 school districts a year-long instructional effort on how to identify and help troubled children. (Details on the

Turn To **(CONFERENCE)** on Page15

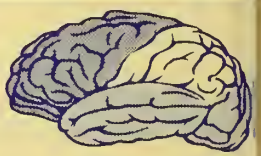
Two Research Centers of Excellence....

The Center for Psychosocial and Forensic Services at the University of Massachusetts Medical Center in Worcester and the Commonwealth Research Center at the Massachusetts Mental Health Center in Boston are funded by DMH. They bring together some of the best minds and talent in Massachusetts to advance treatment and rehabilitation methods for chronic, persistent and severely psychiatrically ill patients. The Center at the University of Massachusetts Medical Center concentrates on Behavioral and Forensic Services. The Commonwealth Research Center focuses on Clinical Neuroscience and Neuropharmacology. This issue of the Bulletin presents a guest column on smoking and schizophrenia from Dr. Eden Evins, attending psychiatrist and researcher at DMH's Lindemann Mental Health Center.



SMOKING and SCHIZOPHRENIA:

Prevalence, Problems, Possible Solutions



By Eden Evins, M.D.

Among individuals with schizophrenia, 74% to 92% regularly smoke cigarettes, compared with 24.7% of the general adult population in the United States who do so. People with schizophrenia also smoke more cigarettes on average per day and attain higher serum levels of cotinine, the primary metabolite of nicotine. Therefore, people with schizophrenia may not only be more likely to smoke, but may do so in a different manner than individuals in the general population.

Cigarette smoking has been identified as the single most important source of preventable and premature death in the country for the last 29 years. Since people with schizophrenia are much less likely to receive adequate, routine and preventative medical care, heavy smoking represents a significant public health problem for this population.

Research shows that people with schizophrenia clearly have greater morbidity and die earlier, even after controlling for suicide and accidental death, than the population as a whole. They are more likely to die prematurely from cardiovascular or pulmonary diseases; women with schizophrenia have been shown to have a greater risk of premature death from cancer.

Successful smoking cessation programs for schizophrenia could reduce this increased medical morbidity and mortality.

Why do people with schizophrenia smoke with such high frequency? The rates are often attributed to possible amelioration of the undesirable side effects of conventional antipsychotic medications. Smoking is often associated with increased ability to metabolize medications, increased antipsychotic medication dosages, and enhanced dopamine release that may reduce muscular rigidity and tremor side effects.

All smokers have generally been shown to increase cigarette consumption after a single dose of haloperidol (an antipsychotic medication). Nicotine improves some haloperidol-induced deficits in cognitive functioning. On the other hand, clozapine treatment, with its relative absence of pronounced side effects, has been shown to reduce cigarette use acutely.

However, nicotine has many effects on the central nervous system that may explain the high rates of smoking among people with schizophrenia. These include: increased attention levels, better concentration, heightened cerebral glucose utilization, and behavioral arousal, as well as increased serum levels of endorphin and other neuropeptides.

Cigarette smoking produces transient normalization in auditory physiology that likely represents improvement in a process called sensory gating. This raises a person's ability to respond to important features of the environment and filtering of irrelevant stimuli. Advanced sensory gating may have a positive impact on other cognitive deficits and reverse negative symptoms associated with schizophrenia. This provides yet another possible reason why people with schizophrenia are more likely to smoke and to have difficulty quitting.

One recent report on patterns of nicotine use in a group of 50 smokers with schizophrenia illustrates the fact that people with schizophrenia often try to quit smoking. The study showed that 96% tried unsuccessfully to reduce smoking and 70% had made a serious attempt to quit. This group had a mean age of 47 years and mean age at onset of daily smoking of 20 years; 46% reported they currently had a serious smoking

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related health problem. In another sample of 24 smokers with chronic psychosis, 70% had made a serious attempt to stop smoking with 35% making 5 or more attempts to quit.

These studies point to the need for therapeutic interventions to support smoking cessation attempts and maintenance of abstinence from cigarette smoking in this population. At the same time, researchers recognize that nicotine may be helpful to people with schizophrenia. Taken together, these points illustrate the need to identify treatment that allows smoking cessation in people with schizophrenia without decreasing attention or increasing mild depression or negative symptoms.

Toward this end, a nine-session Quit Smoking Group program has been designed specifically for people with schizophrenia in collaboration with the Quit Smoking Service at Massachusetts General Hospital. In this group program, strategies are employed to reduce nicotine craving while clinical symptoms are monitored. The Quit Smoking Group is used in outpatient clinics in conjunction with medication treatments, such as sustained release of bupropion (anti-anxiety medication) to help people quit smoking and to determine which therapies are most effective. Researchers are currently working with adults with schizophrenia who smoke more than a half a pack of cigarettes per day and wish to quit smoking.

Dr. Evins is attending psychiatrist and researcher at DMH's Lindemann Mental Health Center, on staff at the MGH Psychotic Disorders Unit and the Harvard Consolidated Department of Psychiatry and has twice received a NARSAD (National Alliance for Research on Schizophrenia and Depression) Young Investigator Award. Her research is supported through grants from NIDA and NARSAD.

THE CHANGING MINDS CAMPAIGN: RAISING AWARENESS ABOUT MENTAL ILLNESS

GETTING IT RIGHT:

Rick Holmes in MetroWest News GOT IT RIGHT when he wrote about a neighborhood protest to the proposal to build a six-unit apartment house in Marlboro where mentally ill city residents could live independently. In "Don't Shun the Mentally Ill" (5/28/9), Holmes, the newspaper's editorial page editor, wrote, "The problem appears to spring largely from a fear of mental illness that goes back centuries. This is a good project being sponsored by a reputable agency. Protesters should start thinking about welcoming their new neighbors, not shunning them."

Judy Foreman in the Boston Globe's Health Sense GOT IT RIGHT in a story about Moe Armstrong. Now living in Cambridge, Armstrong works with Vinfen, a DMH mental health services provider, teaching other people what he has learned about how to live with major mental illness. "Clues But No Answers On Schizophrenia" (6/21/99) educates and informs readers about the science and the personal pain of this brain disease, which Foreman calls "a terrifying illness. Recovery can happen - and did for Moe Armstrong."

GETTING IT WRONG:

Schizophonic? Is it a new illness? A typing error, perhaps? No. " Schizophonic" is the title of a recently released album, a solo by one of the Spice Girls, known as Ginger Spice. The singer called "Schizophonic" a cross between Julie Andrews and Johnny Rotten. Thus, "Ginger" made the common error of associating the word schizophrenia with the notion of split personality or of opposing ideas. Schizophrenia is a brain disease that may cause hallucinations and delusions. It most often strikes young people between the ages of 16 and 25. Although one out of four families in the United States will have a loved one with a mental illness, ignorance about these illnesses add to their suffering. Referring to mental illness with the same standards of accuracy and good taste that apply to any serious illness strikes a blow to the stigma that fuels discrimination.

Bella English (Boston Globe 6/23/99) reviews "schizophrenic girl mags" that send mixed messages to teens about their bodies and their abilities, publications that want "to have it both ways." Schizophrenia is a serious mental illness, not a different point of view. (See above; "Schizophonic." The title of Englishs' article is "Brainless-Chick Chic.

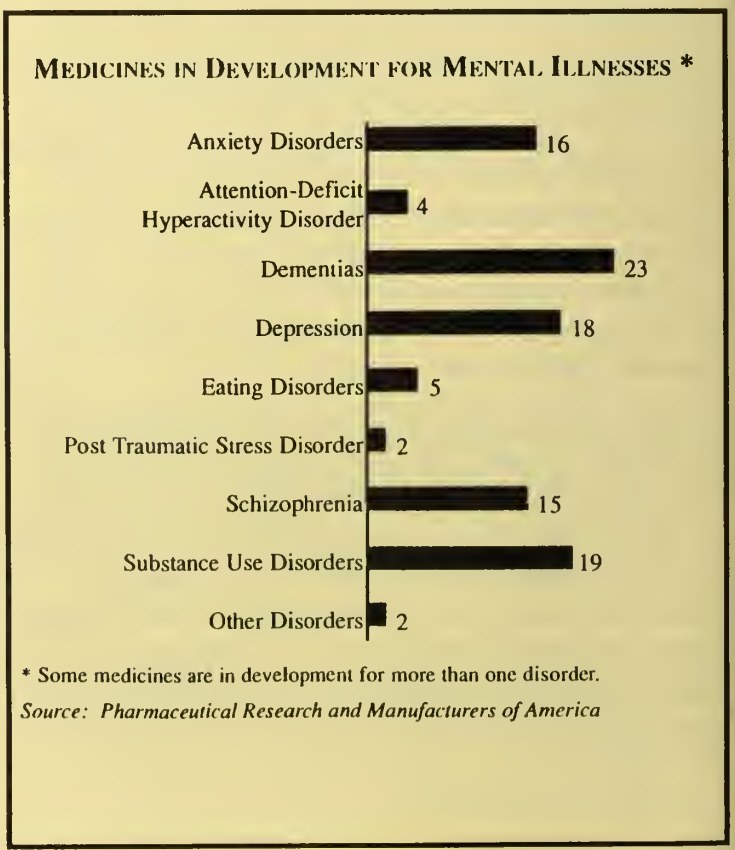
Briefly Noted...

Worried sick? Is it possible? Could anger cause a heart attack or anxiety produce high blood presure? Research suggests that a person's state of mind - moods, thoughts, stress, may play a role in physical illness. According to Roman DeSanctis, director of clinical cardiology at Massachusetts General Hospital, patients with depression are more than four times more likely than patients who are not depressed to die in the six months after a heart attack. To explore the possibility that the brain could have an impact on disease, the Charles A. Dana Foundation has launched the "Brain-Body Initiative" (BBI.) The foundation hopes that BBI willdiscover ways that patients might benefit from the understanding of the brain - body link.

"Priced Out in 1998: The Housing Crisis for People with Disabilities" reports on the housing situation for people with mental illness and other disabilities, particularly for those people who receive Supplemental Security Income (SSI). Compared to the hourly minimum wage of $5.15, the SSI monthly benefit is equal to $3.09 an hour. Copies of the report are available at the website "Opening Doors" http://www.c-c-d.org/doors.html.

"Advancing the National Strategy for Suicide Prevention: Linking Research and Practice"... Developed by more than 450 public health officials, this report was hailed at the nation's first suicide prevention conference by U.S. Surgeon General Daved Satcher, M.D., Ph.D. who noted that suicide is often preventable. "Too many physicians and other health providers are coming into contact with people who are at risk and are not asking the right questions." Every day, an estimated 87 Americans kill themselves; 775,000 more attempt suicide each year. Suicide is currently the eighth leading cause of death in the United States. The conference was organized by the Suicide Prevention Advocacy Network, a non-profit group representing suicide survivors.

The "brain - reward" system allows people to experience the feelings of pleasure and satisfaction that are a part of everyday life. Dr. Alan I. Green of the Commonwealth Research Center suggests that this system may be deficient in persons with schizophrenia and may account for the high use of alcohol and other drugs to ameliorate these deficits. Self-medication may "correct" this underlying clinical lack. Dr. Green's preliminary studies and anecdotal evidence indicates that clozaril can decrease substance abuse in patients with schizophrenia. If clozaril is helping to right the reward effect of the brain, Green says that this principle would appear to deserve further consideration for substance abuse disorders in persons without schizophrenia. To request a reprint of the article (Harvard Review Psychiatry, March/April, 1999: Alan I Green, M.D., Mass. Mental Health Center, 74 Fenwood Road, Boston, MA 02115.



DMH Honors Individuals and Programs at Commissioner's Reception

More than 175 consumers, family members, legislators, advocates, providers and Department of Mental Health staff were on hand recently to honor nine individuals and programs for making significant contributions to people with mental illness in the areas of advocacy, education, research, treatment and rehabilitation. Distinguished Service Awards were presented May 18 by DMH Commissioner Marylou Sudders at a State House reception.

Distinguished Service Award winners in seven statewide categories included: **Representative Nancy Flavin** of Easthampton, co-chair of the joint Committee on Insurance, and **Senator Henri S. Rauschenbach** of Brewster, a member of the Senate Committee on Ways and Means, were honored for working on and supporting legislation that has had or will have significant impact on people with mental illness. **Dr. Dennis J. McCrory,** chief psychiatric consultant for the Massachusetts Rehabilitation Commission, was honored for best exemplifying the concepts of rehabilitation and recovery. **The Committee on the Status of Mental Health Services for Children** was honored for conducting an exhaustive study of issues leading to specific recommendations and improvements in the children's mental health system. Peggy Reiser received the award on behalf of the committee. **The Massachusetts Employment Demonstration Project,** based in Worcester, received the award for research in the mental health field. Cathaleene Macias of Fountain House in New York was on hand to receive the award. The **Taunton Daily Gazette** was honored for contributing in a significant way to educating the public about mental illness. Terrence Mercer, Managing Editor of the newspaper, received the award on behalf of the new staff. **Phyllis Burns** of Marshfield, the second President of the Plymouth Area Chapter of the Alliance for the Mentally Ill (AMI), received a Distinguished Service Award for contributing in a significant way to educating the public about mental illness. **The Engage Program** at the Pine Street Inn in Boston was honored for providing outstanding, creative services to adults with serious and persistent mental illness. Judy Lipton supervises the program and was on hand for the award. **Charles D. Baker**, former Secretary of the Executive Offices of Administration and Finance and Health and Human Services, was named the winner of the Lilo McMillan Award. The honor is bestowed on a person who best reflects the values and qualities held firmly by the late Lilo McMillan of Ayer, a visionary, an activist and a long-time advocate for mental health services. Baker was unable to attend. The award will be presented to him in the near future.

(From top left:) Sen. Henri Rauschenbach, Rep. Nancy Flavin, Phyllis Burns, Judy Lipton, Cathaleene Macias, Peggy Reiser, Dr. Dennis McCrory and Terrence Mercer.

IT IS THE SPRINGTIME OF MY LIFE

By Bonnie J. Twomey

My first experience with the mental health system was discouraging to say the least. My psychiatrist gave me no hope for recovery. She blatantly told me I would "never feel good about myself, never have normal relationships and will never be able to return to work."

My family and I were not referred to any outside agencies, family groups or advocacy agencies. We were basically left on our own. I received no constructive feedback on issues relating to schizophrenia or how to deal with my emotional struggles. I received no help with how to deal with my losses.

After years of unproductive therapy, I gained a new sense of learning how to use it to my benefit. I began to pinpoint stressors, which made my therapy sessions more productive. The first therapist I felt comfortable with gave me advice that will stay with me for a lifetime. She had told me to stop analyzing and that I needed to start to learn how to comfort myself. She gave me constructive feedback the way I needed it; I felt comfortable. This was the beginning of receiving good therapy and being able to deal with issues constructively.

My current therapist is good. She seems to be sincere most of the time. She has shown excitement at some of my accomplishments, and has given me ideas on social activities relating to my interests. My recovery process has been faster and more painless when I have received genuine support and caring. When I receive support from my therapist I feel in a safe place.

It took many, many years to settle within myself. What I needed most of all was to find what makes me happy. My family is important, but I need to take of myself.

I learned to accept my illness and began to learn how to accept living with it. The darkness I feel is incredible. The depression and levels of stress are difficult to manage. I have learned throughout the years to pinpoint what makes me depressed or stressed and to deal with whatever is bothering me head-on. If I do not have an answer, I take it easy, relax, try to have some fun, and deal with it in therapy. Some parts of my life will never be easy, but somehow I've settled with knowing I will always suffer at times. I know I will continue to fight, and love life again in a way I feel comfortable. This is the gift I gave to myself for all the years I had punished myself. I had no choice but to begin to love life again.

There are many ways I needed to rethink and redirect my energies in every stage of my life. With my disability, dealing with everyday ups and downs is extremely difficult. There are times I will go to the lake down the road and walk, reflect, make decisions, and sometimes sketch.

It took many years to find myself using and putting into practice good coping skills. I find exercising helps and I have a great feeling when I leave the gym. I can feel the tension lift off my shoulders when I have a good workout. I learned that keeping busy often helps keep my mind off my-

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The DMH *Bulletin*

A quarterly publication of the Massachusetts Department of Mental Health, reporting state news and relevant information for clients and their families, mental health professionals, vendors of services, and all citizens interested in the goals and mission of this human service agency.

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self. My faith is my major source of strength. It is very personal for me, but it is so important I would not know what to do without my faith. I try to keep a positive outlook on life. I am generally positive, although I can distort reality and feel as though I have nothing. Most of the time, I just do not know how to cope. Many of my skills are innate, and some are learned.

I first realized I deserved no blame for my illness in the fall of 1997. Through educating myself, I realized I was unfortunate to have a brain disorder, which could have occurred at any time in my life. I always thought I had played a role in causing my disability. The blame is indescribable. It is disabling in itself. The pain that was inside me was so ingrained that my body reeked of pain and sadness as I learned I was never to be blamed for this tragedy. It was fate. I would look to the past. What did I do wrong? Could I have changed my destiny? The answer is no.

"I always thought I had played a role in causing my disability. The blame is indiescribable. It is disabling in itself."

I began to deal with the guilt. I learned how to take of myself. I would take time in the morning to reflect on the day ahead, and to relax and enjoy life again to the fullest. My anger subsided and a new appreciation for my family and friends, even strangers, began to emerge. I realized not everyone is bad. I'm not bad. My family is not bad. We are dealt a heavy hand, and we are not alone.

My recovery took a long time to evolve. I learned who I am with and without the illness. I gained enough insight to tell others just enough to let them know I'm not all with it today. My expectations would be put in priority and whatever I accomplished, however small, would be enough. At the end of the day I would feel proud and still easy on myself.

When I lessened the stressors in my life, I had a tendency to put more stressors on. Sound crazy? Learning that I can reduce stressors I put on myself is also learning I have some control in my life. I have learned when to stop. Nobody will take better care of myself than me. It seems impossible at times because I want so much to live a normal life. Yet I expect myself to have normal, realistic goals.

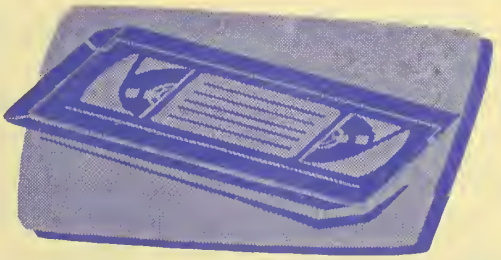
"Living a normal life." That phrase sounds so profound to me. The hardest part of recovery is that we have learned not to know what to expect from ourselves due to a mental illness. Yeah, take a couple of aspirin and take a nap for the rest of your life. What is so sad is that your illness never goes away, yet you can learn to function with it. It hurts. The truth hurts.

I find that part - time work seems to be just enough at this stage of my life. It is difficult for me to work full time and to live independently. I still wish to return to a job that will sustain independent living, and that will keep me happy.

Currently, I am working with a consumer advocacy agency. I have been blessed with great co-workers and a great supervisor. They are aware of my disability and are extremely supportive. After having experienced so many unthankful jobs, my position and the support I have received made me realize there are good people out there who care. It makes a world of difference. My outlook on life has changed over the years. I am more realistic. I still love my childish, positive side with a sense of humor. Although I feel hurt by life I still have a passion to help others, and to be around people. I need to be with people. I began to listen to my heart again.

Bonnie Twomey is a graduate of Northeastern University. She works for the Massachusetts Association for Mental Health and is currently writing her autobiography. In the Springtime of My Life was first published in the Boston University Psychiatric Rehabilitation Journal.

"THE BONNIE TAPES" introduce the viewer to Bonnie and to her family. It tells their story through interviews with her parents, her sister and with Bonnie herself. To borrow these videotapes, call DMH Public Affairs office: 617-626-5187.



50 Years

May is Mental Health Month

1949 - 1999

During this anniversary year, the first week of May was observed as Children's Mental Health Week. The National Mental Health Association (NMHA) introduced a new initiative to alert the public to the significant problem of childhood depression. Although depression in children was once thought to be imaginary, we now know that one in five children and adolescents has a mental health problem that can be identified and treated. Suicide is the third leading cause of death among people aged 15 - 24.

To raise awareness and to help identify potential problems, the week included Childhood Depression Awareness Day on May 4, 1999. NMHA offered a free planning kit called "What's the Matter?" containing fact sheets and suggestions for outreach activities. More information on this project is available by calling NMHA (703) 838-7548.

One of the many mental health events that took place in Massachusetts was the fifth annual "Night at the Wang," featuring the artistic talents of more than 100 young people from seven Department of Mental Health residential programs. This award-winning "Express Yourself" program celebrated its 10th year on May 10 in the Grand Lobby of the Wang Theatre, Boston.

MESSAGES:

- Mental health is crucial for physical health.
- Mental illnesses are real, common and treatable just as, if not more treatable than, physical illnesses.
- Stigma and misunderstanding are serious impediments to treatment and recovery.
- Equal coverage of mental and physical illnesses in health insurance is good medicine.

Metro Suburban Area Offers

Quality Management Symposium

As part of the DMH Metro Suburban Area's ongoing efforts to support quality management initiatives, a symposium on current outcomes measurement strategies was attended by more than 130 individuals recently at Framingham State College. The second annual symposium also offered participants opportunities to share information on quality improvement systems and projects.

Quality Measurement in Behavioral Health: Practical Approaches to Achieving Tangible Results, was co-sponsored by the Area and the University of Massachusetts Medical School. Robert J. Gee, President and Founder of the National Graduate School of Quality Management, the keynote speaker, began the symposium by emphasizing the importance of using data to show tangible results. Also featured were 10 workshops and 14 storyboards presented by the Metro Suburban Area service network. Presentations addressed a variety of topics including: developing a program evaluation to improve operations and track client outcomes; increasing consumer and staff involvement in the community; utilizing an assessment tool to evaluate the participation of individuals in groups; and using quality management and public health strategies to improve consumer health outcomes.

For the second year, symposium evaluations were extremely positive. As one participant stated, "The energy generated from networking was the equivalent of a year's worth of meetings. It brought people together in a unique and satisfying environment."

DOUBLE AWARD WINNER...PAUL BARREIRA, M.D.

Since 1991, the National Alliance for the Mentally Ill has presented its Exemplary Psychiatrist Award at the annual meeting of the American Psychiatric Association. This year, Dr. Paul Barreira, DMH Deputy Commissioner for Clinical and Professional Services, was among the 39 honorees from the U.S. and Canada recognized for their contributions to greater public understanding of brain disorders, their work to eliminate stigma, and their campaigns to uphold the rights of patients and families.

Massachusetts' families also honored Dr. Barreira at the state convention of the Alliance for the Mentally Ill as Psychiatrist of the Year, citing him for "his dedication to providing the highest quality of clinical care to individuals with mental illness."

As Deputy Commissioner for Clinical and Professional Services, Dr. Barreira is a caring and compassionate physician. When accepting his plaque from Barbara Flory, President of the Massachusetts Alliance for the Mentally Ill, he spoke about a painful time in his life. This is a story not told before in public, because he had never wanted to "exploit or use it." He had always wanted his work "to stand for itself."

When Dr. Barreira was a senior in high school, his successful, hard-working father became ill, complaining initially of unidentifiable aches and pains and an unaccountable weakness. He eventually took to his bed, unable to work and finally refusing to leave his room. This soon led to the office of a psychiatrist.

Dr. Barreira's mother was frightened and ashamed. As the oldest of her three children, he was asked to drive her to the appointment with the doctor who would deliver his diagnosis. It was grim. The doctor began by noting how "intelligent and creative" her husband was and then explained that THIS often happened to such people. THIS, in 1963, meant that this man, not yet 50 years old, would need to be institutionalized for the rest of his life. The doctor told mother and son, that THIS would most likely happen to some of the children as well.

Devastated and isolated, Dr. Barreira's mother did not act on the doctor's advice. She decided to withhold the diagnosis from her husband. The family made some moves, matters improved and eventually, Dr. Barreira's father recovered enough to work again. But Paul Barreira and his mother had heard the dire predictions. The experience, as Dr. Barreira says today, was "formative." He knows the bewilderment and terror of families who are "clueless," as his family was, of the world of mental illness. It is just one piece of his life that informs his work, a "work that stands for itself."

Recommended Reading ...

"All human societies have ways of acknowledging and managing behavioral deviation -- the punishment of crime, the care of suffering, the celebration of success -- but, historically, deviations of mind have fallen betwixt and between established categories. Manic depression is considered an illness in the United States, but those who suffer it rarely receive medical benefits comparable to those afforded other grave illnesses. American society has consistently discriminated against those with mood disorders. There will be many benefits from the new genetic knowledge ... the design of new drugs -- improved mood stabilizers and antidepressants, even early intervention for those at risk."

-- Peter Whybrow, "*A Mood Apart*: The Thinker's Guide to Emotion and Its Disorders."

QUICK FIXES OUT, BUT HELP AVAILABLE FOR CHILDREN

On May 10, 1999, Lisbeth B. Schorr, Ph.D., told professionals gathered at the University of Massachusetts Medical School's Department of Psychiatry that children with severe mental illness and their families can be helped and that problems, such as high rates of school failure, single parenthood, child abuse, and even youth violence can be combated. But this can't be accomplished overnight, and it requires fundamental departures from some of the outmoded, historic practices and policies that have constrained those providing care. The following excerpts from her speech:

"I am particularly delighted ... to talk to people who are grappling every day at the front lines with issues I have been trying to understand from afar. ... The most fundamental conclusion from my work of the last couple of decades is that we know so much more about what needs to be done than we are acting on."

Speaking about the school shootings in Colorado, Dr. Schorr said, ... "the massacre at Columbine High School woke us up to the realization that the general unease about something fundamental having gone wrong in America knows no boundaries of class or geography. Even material wealth and suburban comfort cannot wall us off from the ravages of the alienated in our midst. ... We yearn to learn something from the Littleton tragedy, something that could inform our efforts to fashion a constructive response."

Three conclusions can be drawn from this incident. "First, guns, and access to guns does matter. ... Secondly, isolation matters. We know very little about the way these youngsters were isolated from caring, connecting adults. ... Third, we can be pretty sure that there was no one cause and that there can be no single cure for what went so very wrong. ...

"It isn't just about any one thing. Many of you know the story of what happened in Boston, when a group of ministers set out to do something about the mounting number of young people killed with guns. Now, ten years later, Boston has had only a single gun-related youth homicide in the last three years. ...

"Preachers, teachers, police, probation officers, youth workers, and parents organized to cut juvenile violence by removing weapons, reclaiming parks and sidewalks, tutoring at-risk kids, supporting families, lessening isolation, and sharing information to resurrect the civil life of their jobless, drug and crime-infested neighborhoods. What they have accepted in Boston ... is that no single, magical intervention will stop juvenile violence, and that you don't get results overnight. But that ultimately, if you do it thoughtfully and strategically, and if you join together to combine what works, you get results! ...

"From the successes of the last 30 years, we have learned that interventions that change lives of high risk youngsters have common attributes. They are comprehensive, flexible ... they deal with kids as parts of families ... they deal with families as parts of communities, and are deeply rooted in the neighborhood ... they have a clear coherent mission ... they start early ... and staff build strong relationships based on mutual trust and respect, often going well beyond boundaries of their job descriptions, and finding new ways of defining professionalism.

"We yearn to learn something from the Littleton tragedy, something that could inform our efforts to fashion a constructive response." -- Lisbeth B. Schorr, Ph.D.

As Dorothy Stoneman, founder of YouthBuild, says, " 'Staff should be encouraged to go to funerals and hospitals, to give out their phone numbers, and to be on call 24 hours a day. ... When staff simply do what they are paid to do, trainees remain agnostic or negative concerning whether the staff really care ... and can be trusted not to betray or to abandon them."

"Such an obvious show of caring is an important signal to participants that this time it will be different from previous experiences characterized by excessive formality and social distance ... If we know that effective programs are characterized by flexibility, comprehensiveness, responsiveness, front-line discretion, the ability to see children in the context of families and families in the context of their neighborhood, and respectful, trusting relationships — why do we have so much trouble spreading and sustaining our successes?"

Funding "is the great hidden paradox. The attributes of effectiveness are consistently undermined by the institutions and systems on which they depend for funding and

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legitimization, institutions and systems on which they depend for funding and legitimization.

"Perhaps nothing interferes more profoundly with our acting on what we know than our continuing reliance on isolated projects and demonstration programs. ... Although funding might be only at token levels, funders prided themselves on delivering identifiable program benefits to narrowly drawn constituencies for which they could take credit. Adding yet one more category, whether or not it fit with what was already there, became particularly attractive as the chances for new universal programs and major new public spending began to dim, and as our faith in the effectiveness of government efforts dimmed. ...

"If we are serious about wanting the model to become the norm, if we want to create a culture in which people don't have to sneak around in order to do the right thing, and we don't want 'the right thing' to disappear the moment it reaches more than token size, we must become much more strategic than we have been in the past.

"And how do we become more strategic? Let me count the ways. My work of the past several years, that I report on in COMMON PURPOSE, suggests there are just a handful of strategies that seem to be essential to efforts to spread and sustain successful interventions:

1. "Efforts that succeed in spreading and sustaining effective interventions focus unrelentingly on results ... to tame bureaucracies, allow front-line discretion, to facilitate collaboration, to assure that investments connect to outcomes and are producing agreed-upon results.

"In public systems, a focus on results becomes a way of taming bureaucracies in a world where we have been so eager, as a body politic, to eliminate the possibility that public servants will do anything wrong, that we have tied their hands at the front lines in ways that have made it virtually impossible for them to do anything right. ...

2. "Successful systems change occurs when leaders articulate a clear commitment to a long-term process of change. ... When leaders validate the perception that the way we've done things in the past isn't working, and that we need to make fundamental changes to accomplish our objectives, they legitimate the hard work and the long-term commitment that makes change possible, that allows institutions that have learned to do things one way to learn ways of doing new things in new ways, which involves ... a continuing process of learning, reflecting upon learning and then learning some more.

3. "Successful efforts to spread a proven model don't clone, but replicate the essence of a successful intervention while allowing each new setting to adapt many of its components to their particular need and strengths, and in response to experience the programs and institutions that effectively serve depleted neighborhoods are deeply rooted in the neighborhoods and reflect particular neighborhood ends and strengths.

"One of the most difficult lessons for policy makers to learn — that successful interventions cannot be imposed from without. ... Successful programs distill the essence of an intervention and then allow it to be shaped locally to respond to the needs of particular populations, and to assure that local communities have a genuine sense of ownership.

4. "Successful scale-up efforts create new kinds of partnerships: between formal agencies and neighborhood groups, and between local reform efforts and outside intermediaries.

5. "Environments that support and sustain effective interventions also create new vertical alliances, between program people and community leaders who know what needs to be done locally, and the outsiders who can reach the levers of policy change and thereby begin to change the rules that govern how accountability is maintained, how the money flows and how the regulations are written.

6. Now comes "the crucial matter of community building — efforts to put together what works and to target resources to transform entire neighborhoods. Community builders know that social disorganization undermines family formation, family resilience, and family success and increases the chances of violence. They know that you cannot improve outcomes for large numbers of children without fostering more family-supportive environments, especially in the inner city.

"Comprehensive community initiatives take a long-term view of change, and recognize that success is based on employing multiple solutions to multiple problems. They link their own efforts to those of others, be the efforts to improve the justice system and increase public safety, efforts to improve services and schools, to expand economic opportunities, or to improve housing. ...

"The loss of community, like most contemporary ills, has hit the poor and persons of color the hardest. The decline of manufacturing, the disappearance of well-paid jobs for the unskilled, racial discrimination in both hiring

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and housing, the decreasing value of income supports, inferior and overwhelmed schools and services, the flight of the middle class to the suburbs, crack and the crack trade have combined to form the inner city deserts, inhospitable to the healthy human development.

"People engaged in community building today recognize that services are not enough. That's why they act in more than a single domain, be it through early education, school-based services, school reform, teen pregnancy prevention, family reservation, community policing, community drug courts, or expanding economic opportunity. The new neighborhood transformation initiatives are comprehensive and put together enough of what works to restore hope in depleted inner-city neighborhoods.

"The new comprehensive initiatives make use of the information, expertise, and wisdom that can only come from the neighborhood itself, but also develop the capacity to mobilize the funding, influence and knowledge about what works from outside.

"When it comes to these complex collaborative efforts, we must recognize that it will be impossible to be certain about which aspect of the intervention caused the positive results. ...

"That's what the Boston story I referred to earlier illustrates. When you ask, what happened to cause a dramatic drop in youth homicide, whether you ask the preachers, the teachers, the academics, the police or the residents, they all say it couldn't have happened without all of us having worked together. ... People engaged in community building today recognize that services are not enough. That's why they act in more than a single domain, be it through early education, school-based services, school reform, teen pregnancy prevention, family preservation, community policing, community drug courts, or expanding economic opportunity. ... The new comprehensive initiatives make use of the information, expertise and wisdom that can only come from the neighborhood itself, but also develop the capacity to mobilize the funding, influence and the knowledge about what works from outside.

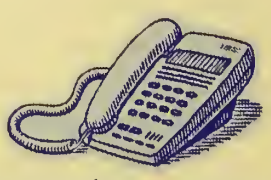
"When it comes to these complex, synergistic efforts, we must recognize that it will be impossible to be certain about which aspect of the intervention caused the positive results. ...

"As we come to the end of the 20th century, we may no longer be able to count on heroic figures to mobilize us to act, but perhaps we can be mobilized on behalf of a shared heroic idea, the idea that we are all interconnected, that we're all in this together, and must share the burdens and pool some of our rich resources so that all our children will have a fair chance to succeed, and so that we can achieve our best possibilities as a nation of opportunity for all. Surely we can tame our rampant individualism enough to agree that we cannot allow the richest country to declare bankruptcy in its civic life. ...

"If we act strategically and boldly on what we now know, we would go far toward realizing our common purposes, toward breaking the cycle of disadvantage, and toward strengthening American families and neighborhoods, so that all our children can grow up safely, and with a realistic stake in the American dream."

Lisbeth B. Schorr, Ph.D., is a lecturer in Social Medicine and Director of the Project on Effective Interventions at Harvard University Medical School.

INSURE KIDS NOW 800 NUMBER



Insure Kids Now is the name of a hotline that will connect callers directly to their appropriate state agency to help parents or guardians enroll eligible children. The State Children's Health Insurance Program (SCHIP) became an entity last year and $24 billion over five years was allocated by the federal government to help states expand health insurance to children whose families earn more than traditional Medicaid allows, but not enough to afford private health insurance.

Massachusetts is one of eight pilot states now offering the Insure Kids Now program. Other participating states are Colorado, Delaware, Idaho, Indiana, Pennsylvania, South Carolina and Utah. To make enrollment more user-friendly, the National Governors Association, in conjunction with the White House, created a single national number that will connect a caller with knowledgeable SCHIP staff in the family's home state. Dialing 1-877-KIDS-NOW will put you in touch with a person who will help.

(CONFERENCE) Cont'd From Page 3

application process: Bob Chase, National Education Association, President. 202-822-7200).

The conferees heard that more than 19 million adult Americans will suffer from depression this year, according to the National Institute of Mental Health, and 55 million people across the county will experience a mental illness during their lives. The World Health Organization now calls depression the leading cause of disability in the world. The most devastating consequence of mental illness is suicide.

The conference heard from speakers with depression, bipolar disease and other mental illnesses describe not only what it was like to be ill, but to live with the stigma associated with it. Some were famous; all had noteworthy things to say. Mike Wallace of 60 Minutes spoke about his secret battle with depression that once laid him "lower than a snake's belly." Robyn Kitchell, the mother of a manic-depressive son, described what it is like "when mental illness hits puberty - "boy, is that a ride."

"The day I was diagnosed [with bipolar disorder] was one of the happiest days of my life," Lynn Rivers, a Michigan Congresswoman, told the standing room audience. "Finally, I wasn't bad or lazy or whatever people might have thought. I was sick. I was finally dealing with something that was not my fault."

Tipper Gore talked about her struggle with depression 10 years ago after her then 6-year-old son, Albert, nearly died when hit by a car. John Wong outlined his battle with schizophrenia that went untreated and led to an assault on his father. Wong, a California resident, now works at the Asian Pacific Family Center and teaches English as a second language.

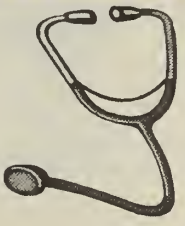
Marylou Sudders, Massachusetts Department of Mental Health Commissioner, was one of only three state mental health commissioners invited to attend the June 7 conference at Howard University in Washington, D.C. The conference's focus on mental illness, the stigma and discrimination surrounding it, and its impact on family members, friends and others closely parallels themes encompassed in the state Department of Mental Health's two-year-old Changing Minds campaign. "My hope is that the frankness evident at the conference will help us all dispel the myths about mental illness and to stand up and speak out on issues like insurance parity and stigma," Commissioner Sudders said.

President Clinton and conferees decried the basic unfairness of treating mental illness differently from other medical ailments. Clinton asked Congress to guarantee that people with mental illness get the same insurance benefits for depression as they do for heart disease, asthma or any other physical ailment. He supports a bill introduced by Senators Pete Domenici and Paul Wellstone to close huge loopholes in federal legislation that currently allows caps on hospital stays and outpatient treatments. The bill would also provide for parity on deductibles and co-payments in treatment of severe mental illnesses such as schizophrenia. A broader House bill would also include insurance parity for substance abuse treatments.

Clinton officially announced that federal employees would soon have coverage for mental illness that is as good as coverage for other illnesses. Clinton said the federal government had sent a letter to the 285 health plans it offers telling them that they must comply. The plans cover about 9 million employees. The Massachusetts Group Insurance Commission implemented similar insurer coverage for state employees effective July 1.

When President George Bush proclaimed the 1990s the Decade of the Brain, the gains in research and the improvement in treatment options for people with mental illness could not have been imagined. Nor could such a White House conference. This conference marks the Decade of the Brain, not as an end point, but the beginning of more understanding of brain diseases, leading to more effective treatment, prevention and cures.

REPORT FROM SURGEON GENERAL TO DISPEL STIGMA



Due out this fall, Dr. David Sacher's report on mental health is designed to remove the stigma Americans attach to mental illness. The report will not make recommendations regarding treatment or prevention, but will address mental health across the life span. It will emphasize that mental health should be treated as part of an integrated public health prevention and response strategy.

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Mental Illness Awareness Week

October 3-9, 1999

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